

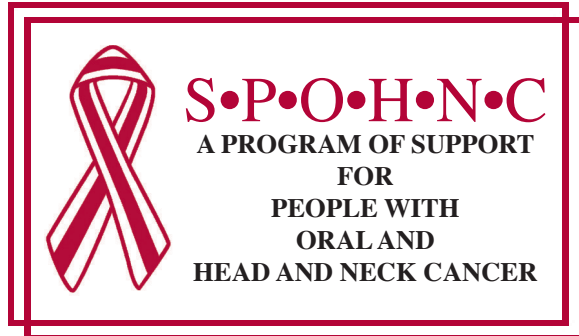
NEWS FROM S·P·O·H·N·C



VOL. 25 NO. 2

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

OCTOBER 2015



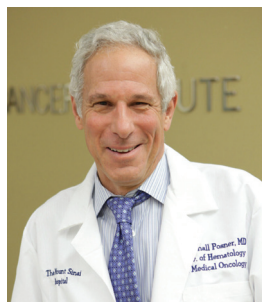
Immunotherapy

Marshall Posner, MD
Krzysztof Misiukiewicz, MD

Introduction

The vast majority of head and neck cancers arise from the squamous mucosa of the upper aerodigestive tract. In the United States, head and neck squamous cell carcinomas (HNSCC) account for approximately 3% of cancers worldwide with 60,000 new cases diagnosed each year. Head and neck cancer is highly curable and the prognosis is excellent when detected early. Despite the decrease in tobacco use, a known risk factor for HNSCC, the incidence of tonsil and base of tongue cancer (oropharyngeal cancer) began to rise over the last 4 decades. This rise has been attributed to increased human papilloma virus (HPV) caused cancers of the oropharynx. Patients with HPV associated oropharyngeal locally advanced cancer have a significantly better prognosis at presentation compared with patients whose disease is not associated with HPV. Most HPV caused oropharynx cancer is caused by a high risk subtype, HPV16.

Even though patients with locally advanced HPV16 induced tumors have good prognosis at presentation and many are cured by surgery, chemoradiotherapy or sequential therapy, it is well known that the prognosis of patients with recurrent and/or metastatic (R/M) HNSCC regardless of their HPV status is dependent both upon patient-related and disease-related factors.



Current treatment options for patients with metastatic or advanced recurrent disease includes single agent chemotherapy, combination chemotherapy, and targeted agents either alone or in combination with conventional chemotherapy, and best supportive care. Several randomized trials have shown that most combination chemotherapy yields superior response rates, but is also associated with increased toxicity over single agent chemotherapy. Currently a combination of platinum, 5- fluorouracil and cetuximab based on The Extreme Trial, showed an improvement in overall survival in recurrent and metastatic patients over a chemotherapy doublet and as of today is considered standard of care.

Traditional chemotherapy, which primarily attacks rapidly dividing cells, and targeted therapies, which interfere with key molecular events in tumor cells that drive tumor growth and invasion, are entirely different from immunotherapy. Immunotherapy is based upon the biologic notion that the patient's own immune system may play a major role in suppression or even eradication of malignancy and can be harnessed to treat the cancer. Knowing that tumors evolve ways to avoid the immune system, the main goals of immunotherapy are first, to help in the recognition of cancer as foreign by the immune system, second to stimulate a robust immune response and lastly to block inhibition by the tumor of the immune system, a tumor specific process that blocks immune control and recognition of the tumor. Different approaches have been undertaken to stimulate immune responses against cancer such as monoclonal antibodies, therapeutic vaccines, immunomodulators, adoptive T cell transfer therapies, and checkpoint inhibitors.

Immunotherapy

Monoclonal Antibodies

We produce antibodies to fight infections. Monoclonal antibodies (mAbs) are highly specific antibodies; created in a laboratory, that target only specific antigens. Some mAbs attack normal proteins on cancer cells and either block function, stimulate the immune system for an immune attack, or block the actions of molecules that alter immune cell function. As an example, cetuximab, FDA approved for HNSCC, is an IgG1 antibody that in addition to cancer growth inhibition through blocking a growth factor action on tumor cells may also act via antibody-dependent cell mediated cytotoxicity (ADCC), a mechanism of cell-mediated immune defense against tumors. Others, like Panitumumab, fully human IgG2 antibody, do not induce ADCC but it is unclear how these differences impact effectiveness. This provides an example that only some monoclonal antibodies generate an immune response. Clinical trials evaluating monotherapeutic and combinatorial mAb strategies, including combinations with other forms of immunotherapy are of high priority.

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Cancer Vaccines

Cancer vaccines can be categorized as preventive or therapeutic. Preventive vaccines, which are commercially available, block infection and do not attack infected cells. We know that some cancers are caused by infectious agents such as HPV. The anti-HPV vaccine Gardasil is a preventive vaccine and has no role in treatment of established cancer. In contrast, the benefit of cancer treatment vaccines lies in their ability to stimulate the cellular immune system response and stimulate an attack by the body’s immune system on cancer cells. It is well known that tumors are not sufficiently different from normal cells to be recognized as foreign therefore the immune response may not be strong enough to attack the cancer cells. In general there are requirements necessary for vaccine success. The tumor cell must express an antigen that is recognized as “foreign” and included in a vaccine, and then the antigen in the vaccine must create a specific cellular immune response. More importantly, the vaccine antigens must involve other components of the immune system to enhance the power of the response.

Many anticancer therapeutic vaccines currently are being tested in clinical trials. Some of them use a bioengineered live bacterial vaccine that has protein from HPV16 virus that once absorbed into the cancer cells, along with the bacterial inflammation, generate a multifactorial immune response that can infiltrate local and distant malignant tissues and destroy tumor cells. The vaccine has no direct effect on the tumor tissue, but is designed to stimulate the patient’s own immune system to generate an effective immune response targeting a tumor-associated antigen which is a necessary growth factor for the cancer cells.

Another type of vaccine is made from patients own cancer cells prior to undergoing chemotherapy and radiation (CRT) and given after CRT is completed to prevent tumors from recurring. They are designed to educate the immune system to identify and kill the cancer cells from which they were derived at the very early stage of development to keep patients in remission.

DNA-based vaccines enable the patient’s body to produce HPV16 viral antigens in order to induce a stronger targeted immune response against HPV-associated diseases such as head and neck cancer. Some preliminary data showed that this method generated significant antigen-specific immune responses in 3 of 4 patients with head and neck cancer associated with human papillomavirus (HPV) types 16 and 18. Promising results and an acceptable side effect profile hopefully will be confirmed in a larger study.

Immunomodulators

Immunomodulators are drugs that are either used alone or in combination with other immunotherapies to boost the immune response. The benefit of immunomodulators comes from their ability to stimulate natural and adaptive defense mechanisms, such as cytokines, which enables the body to help itself. They usually work by helping the immune system to collaborate with antigen presenting cells by boosting recognition of self and foreign antigen complexes on immature, developing immune cells.

Adoptive T Cell Transfer

Adoptive T Cell Transfer is a method whereby immunogenic Tumor-infiltrating lymphocytes (TILs) are very specific to particular

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cancers and with the best antitumor activity are isolated and grown in culture to produce a large number. Once successfully modified and grown, TILs can be re-introduced into the patient by infusion with the goal of improving the immune system's anti-cancer response. TILs that are used in this method represent an immune cell population that recognizes tumor antigen but since they are not strong or frequent enough to eradicate the cancer on their own, they have to be extracted from the patient and then stimulated and grown. Promising results were reported in patients with metastatic or locally advanced refractory or recurrent cervical HPV positive cancer. Patients were treated with TILs cell infusion that was preceded by lymphocyte-depleting low dose chemotherapy and was followed by administration of aldesleukin, a drug that helps increase production of several different components of the immune system found in the blood, including T lymphocytes and natural killer cells. Three of nine patients on this study experienced objective tumor responses (two complete responses and one partial response).

Checkpoint Inhibitors

Activation of anti-cancer immunity begins when T-cells recognize peptide fragments of intracellular cancer specific proteins that are expressed on the surface of antigen presenting cells (APCs). The pre-existing anti-cancer immune responses are inhibited by cytotoxic T-lymphocyte antigen 4 (CTLA-4) receptor and the programmed cell death 1 receptor (PD-1) that once blocked will unleash patients' antitumor immune response. Programmed death-ligand 1 (PD-L1) is a protein that is expressed not only on normal immune cells but also on cancer cells. Interestingly in some cancers high tumor expression of PD-L1 was associated with increased tumor aggressiveness but also may suppress antitumor immune cells. Drugs that block the CTLA-4 or PD1 pathway are known as checkpoint inhibitors and boost the immune response by eliminating suppression. These agents look very promising and are approved for use in a number of cancers, but at this moment can be only offered in the form of a clinical trial for head and neck patients.

Ipilimumab is approved in treatment of metastatic melanoma and targets the

CTLA-4 and is being studied in HNSCC. Several large clinical trials with compounds that exploit the PD1 pathway are open and enrolling patients. This enormous interest and effort is based on a study that was presented at the American Society of Clinical Oncology (ASCO) 2015 Meeting with 132 patients with R/M HNSCC treated with pembrolizumab (200 mg every three weeks). The objective response rate was promising and was seen equally in both HPV positive and HPV negative disease. Even with short follow up, some of those responses lasted more than 6 months and were considered very durable.

Challenges and Future Directions

There are some differences between chemotherapy and targeted therapy vs. immunotherapy in several important respects. When evaluating response to immunotherapy, patients should be aware that a transient worsening of their cancer, manifested either by enlargement of known tumor or the appearance of new tumors can rarely occur before the tumors stop growing or regress. Therefore patients should be cautioned before stopping therapy prematurely. It may be hard for patients as well as the treating oncologist to distinguish whether this transient worsening represents a tumor progression, where the current treatment should be stopped, or expected inflammatory response to therapy where the current treatment should be continued. Also many patients may not see tumor shrinkage. Instead, there may be a prolonged tumor stabilization that is clinically significant and important. More often slow but continued disease regression is frequently observed well after completion of the initial therapy. As immune checkpoint blockade and other immune-based therapy approaches are studied, we may see broad treatment advances. However, an important question has to be asked: "how do we select patients whose tumors will respond to these therapies." Preliminary data suggest that tumors with high rates of somatic mutations have a higher chance of benefiting from immune checkpoint blockade than tumors with lower rates of somatic mutations, meaning more genetically abnormal and complex the cancer is higher the chance for response and benefit. One of the challenges for immunotherapy will be the

supposed resistance of tumors with few mutations or with a "non-inflamed" tumor microenvironment. On the other hand, in some trials PD-L1 expression has been used to evaluate the response based on its level. The more PDL-1 present the more likely the tumor will respond to PD-1 directed therapy but lack of standardization in those tests makes it difficult to make any strong conclusions.

As a result of recent findings with immunotherapy in many cancers with limited options, several new agents advanced into the clinic. However, to date, none have been proven to have significant benefit in HNSCC and have not been approved pending the outcome of current trials. Large numbers of single agent and combination trials have been initiated, most based on blockade of the PD-1/PD-L1 pathway or blockade of CTLA-4. Presently, chemotherapy is the standard treatment for cancer; however, conventional treatments expose patients to many side effects and frequently lead to the development of early drug resistance. On the other side, low dose chemotherapy appears to act on immunomodulatory processes and may help the body fight against tumor cells, with fewer and less severe side effects. As we gain more knowledge, future clinical trials may combine the "old" and "new" methods of treating cancer as the "old" chemotherapy may damage cancer cells, free the cancer antigens and make them more "visible" for immune systems to recognize, and the "new" immunotherapy can "unleash" and "empower" our natural immune resources to fight the cancer. With recent increasing incidence of HPV16 HNSCC, and hopes to reduce post radiation late side effects, an effort should be made to define the role of immunotherapy in future trials that offer deintensification approaches. As reported HPV positive patients treated with chemoradiation have high PD1 expression on immune cells and high level of myeloid cells that suppress immune response after radiotherapy completion. This observation provides a rationale for checkpoint inhibitors and other forms of immunotherapy for HPV positive patients.

In a final conclusion, overall participation in clinical trials remains a priority for patients with this disease in order to redefine the optimal approach to treatment and to further improve outcomes.

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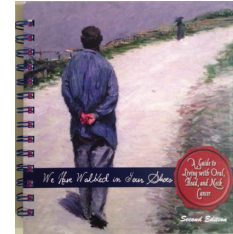
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Editors Note: Dr. Marshall Posner is a Professor of Medicine and Director of the Human Monoclonal Antibody Laboratory in the Department of Cell and Gene Therapy at Mount Sinai School of Medicine. He is also Medical Director of the Head and Neck Oncology Center at the Mount Sinai Medical Center, and Medical Director of the Clinical Trials Office for the Tisch Cancer Institute. Dr. Posner has been an advocate for clinical research and multi-disciplinary care in head and neck cancer.

Dr. 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.

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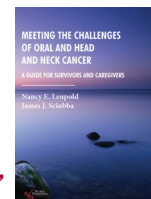
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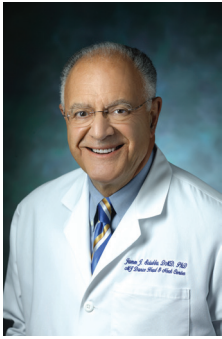
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A Message from the Vice President

In June of 1990, following treatment for oral cancer, Nancy Leupold experienced many of the same difficulties as other head and neck cancer patients. She looked for a group where she could find support and information. Nancy soon discovered that no such group existed.



With the encouragement of her surgeon, Dr. David Wolk and myself, Nancy founded the first support group for people with oral and head and neck cancer. I have been involved with this outstanding organization since the very beginning, and have seen it grow, change, and continue to meet the needs of those who have bravely faced the diagnosis and treatment of oral, and head and neck cancer.

No one should face any type of cancer alone. SPOHNC has been here for almost 25 years, making certain that no one experiences the absence of encouragement, by providing one to one support through its patient and caregiver match program, and within the more than 125 Chapter Support groups where newly diagnosed and patients in various phases of treatment and their families can spend time with others who have traveled their journeys. In part this is accomplished by the availability of several educational resources and publications within the SPOHNC array of offerings including two volumes of a resource guide cookbook, specifically designed for those with eating and swallowing difficulties, entitled *Eat Well – Stay Nourished, Meeting*

the Challenges of Oral and Head and Neck Cancer – A Guide for Survivors and Caregivers, and most recently, the return of the updated *We Have Walked In Your Shoes – A Guide To Living With Oral and Head and Neck Cancer – Second Edition*, which is now available for purchase. Each day, newly diagnosed patients and their families contact SPOHNC, seeking help, so they don't have to face their journey, alone. How has SPOHNC helped you?

As the United States' only patient support organization of its kind for those affected by the diagnosis and treatment of oral, head, and neck cancer, SPOHNC offers you a wide range of services, programs and opportunities that provide a solid value for your membership dollar.

Why not join SPOHNC? Be an integral part of the inspiration and hope that is offered to those who are just beginning their cancer journeys. Becoming a member of this valuable organization will help support the FREE programs and services of support that SPOHNC is able to offer – the programs that have helped individuals like you, your family member, or perhaps a friend.

Become a Member of SPOHNC – and receive the following benefits:

- “News From SPOHNC” - 8 issues/year of print or electronic newsletters which include feature articles written by distinguished oral, head and neck physicians and professionals, poignant and supportive stories shared by survivors and caregivers, the latest information about head and neck cancer treatments and side effects, human interest stories and highlights from chapter events held throughout the country.

- Access to SPOHNC's 125 + chapters throughout the U.S.
- Access to SPOHNC's National Survivor Volunteer Network matching program of more than 200 survivor and caregiver volunteers.
- Access to archives of past newsletters on SPOHNC's website.
- Opportunities to engage in conversation on SPOHNC's Facebook group and page.
- Opportunities to learn about events within the organization and around the globe.
- Access to additional resources via direct contact with SPOHNC's Outreach staff.

Help SPOHNC to provide a voice to help increase awareness, educate others and help meet the needs of oral and head and neck cancer patients and their families.

If you have sent in your membership fee of \$25.00, thank you. If you're not sure if you are a member, please call SPOHNC at 1-800-377-0928 to find out. You can also become a member at www.spoync.org.

SPOHNC values your continued commitment and appreciates your financial support in the form of a membership. It helps SPOHNC to continue to do what it does best.

On behalf of the Board of Directors of SPOHNC, and those patients, survivors, caregivers and families that SPOHNC continues to assist each day, we thank you for becoming a member of SPOHNC.

Sincerely,

James J. Sciubba
James J. Sciubba, DMD, PhD
Vice President
SPOHNC

Editors Note: Dr. Sciubba is the past director of Dental and Oral Medicine Division at Johns Hopkins Medical Center in Baltimore, Md. and is the Co-founder and Chairman of the Medical Advisory Board for Support for People with Oral and Head and Neck Cancer (SPOHNC). He is board-certified through the American Board of Oral and Maxillofacial Pathology and is a professor of Otolaryngology - Head & Neck Surgery at Johns Hopkins School of Medicine, as well as an Emeritus Professor of Oral Biology and Pathology at S.U.N.Y., Stony Brook, New York. He currently is a Consultant at the Milton J. Dance Head & Neck Center in Baltimore, MD. His extensive expertise in the diagnosis and treatment of oral, jawbone and salivary diseases has made him a world authority. Dr. Sciubba has authored several books and over 200 scientific papers, chapters and abstracts.

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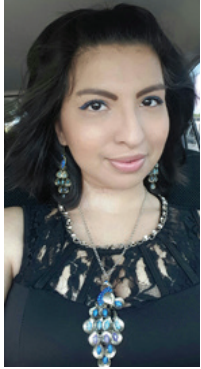


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Time for Sharing... Two Dogs, Two Diagnoses, One Hard-Headed, Strong-Willed Young Woman

When I turned 22 back in June of 2012, I was on the up-and-up of life and making plans for my career as an Industrial Engineer after I graduated. I had the usual college student life – I had friends, I went to school,



I studied, I went out every once in a while. But almost two months later, after my dad made me go get a sore on my tongue checked out, my life was turned upside down. “You have cancer,” my ENT said, staring at the paper and then at me, “and you said you’ve never smoked?” I looked at

him in shock. “No. I have never even HELD a cigarette in my life.” As I struggled to find words and to clear the fog in my head, I semi-stumbled over to the check out desk and texted my best friend immediately while I waited for them to tell me how much I owed. “I have cancer,” I said. Her response was a well-earned, “WHAT?!” followed by, “That’s not possible!” After paying \$50 to be told the news that would change my life forever, I semi-stumbled yet again to my car. I called her and we had a short conversation about how this could have happened, how impossible it was, what I would do, had I told my parents yet, the questions went on and on. When I got to my apartment, my roommate was outside washing his car. I walked past him with a solemn look on my face that made him finish up what he was doing quickly before jumping up the steps to ask me what happened. Before he got inside the apartment, I called my mom and told her the news. She didn’t know what to say, other than “Okay. Oh my god. Okay.” Since my dad was at work, I couldn’t let him know right away so I sent him a text to call me ASAP, and then I called my brother and let him know.

My ENT sent me to his partner in the clinic a week later, who suggested the closest, biggest cancer hospital that he could think of, and referred me there. Thankfully, my parents were there with me to help me make the decision, although there wasn’t much of a decision to make – going to the bigger hospital meant bigger chances of survival and better quality of life, which,

as a young adult, is especially important when you’re not even out of college having to face something like cancer. Later that same day, a Monday, I got a phone call. The hospital wanted me there that Thursday, so my parents and I arranged all our things, got into my mom’s car, and left.

The rest of that week was a blur. Doctor after doctor, appointment after appointment, and eventually I was prescribed pain pills just so I could eat. I kept smiling as I met every doctor, but when I met my now radiation oncologist, I started to cry when she told me the side effects. Little did I know, she would be one of the most supportive and important people in my cancer journey.

My surgery was scheduled for August 20th of that year, and after they biopsied the tumor again they prescribed 30 rounds of radiation, but no chemo. I had Stage IV(A) squamous cell carcinoma of the tongue, at 22 years old. The whole time since I was diagnosed I’d kept my cancer quiet – I didn’t want people to see me as a victim, or call me a “poor thing” or think that I was going to die. Only my closest friends knew, as well as my close family, and after they removed about 1/3 of my tongue and 50 lymph nodes, as well as a skin graft to put on the space left from the glossectomy, I started radiation two weeks later and prepared for the worst.

I didn’t know at that time what I would lose from the diagnosis of having cancer. A lot of young adults at my age are very immature, and don’t know how to handle a situation like this, so they’d either say something awful or wouldn’t say anything at all. My roommate was one of the ones that I felt didn’t know what to do with this situation, even though I considered him like a brother to me. The guy I was dating disappeared completely, even though we’d been seeing each other for almost a year. So-called “friends” dropped out of my life like flies, even after knowing that I needed support and love in the toughest moments of my life. It was amazing to see that in a tough situation, the people who really loved me, like my family and best friend, Sarah, would always be there for me and be supportive, no matter where I was in life.

I went back to work, which was my internship at HP, a week after coming back from treatment. Some people treated me differently, some didn’t. There was a lot of

both support and ignorance, but thankfully people treated me mostly like usual. Most of them didn’t even know where I’d been, and after I told them, they were shocked to know I was back so quickly. I was on a liquid diet then, surviving only on Carnation Instant Breakfast and working 20 hours a week.

When I came back from treatment at the end of October, I immediately rang up the phone number I had for the local SPOHNC group I’d found online and reached Jack Igleburger, the Facilitator of the local chapter in Northwest Arkansas. I chatted him up and asked him a few questions, and after he’d answered all of them, he said “You sound awfully young to have gone through all that. How old are you?” After I told him, he was shocked, but glad that I’d called him and happy that the group would get to meet me at the next meeting in November. I have missed only one or two meetings since, and I can honestly say going to that group is one of the best decisions I ever made for myself. I have felt so welcome, loved, and have been almost adopted as the daughter of the group, and I couldn’t be any happier.

When December rolled around, I got the sudden urge to go to the animal shelter. I was greeted by this lady who asked me what I was looking for, and after explaining my situation, she said, “I have the perfect dog for you.” Out came Thane a few minutes later, his white hair long, matted, and dirty. He came straight for me and sat at my feet, and I looked at him and smiled. She showed me another dog and I immediately said, “I think the other dog is the one for me.” He was affectionately named “Ernie” at the time, and I took him home without a second thought. I gave him a bath the next day, and got him professionally groomed and bathed a few days later. I took him with me to Fort Smith, Arkansas where my parents live (I live an hour or so away in a city near the University of Arkansas), and everyone fell in love.

Things only got better and better as the months passed on, and it took a month or so after I was done with treatment for me to begin eating a soft diet, and then eventually a full, regular diet. I was so excited every time I went back for a checkup, because I could show them and say “Look at me! Look at how much better I’m doing!” and actually be excited about GAINING weight! But, it was

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Visit the SPOHNC website at www.spoync.org

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during one of those routine checkups that I got all the signs that my cancer had come back without being told yet – extra tests, the carefully chosen words of nurses, the guarded words of doctors, and then...BAM. “Your cancer has come back.”

I cannot explain how angry I was when I was given the news. How could it be possible? I’d done everything, anything they asked me to do. I was a good little patient. But the tests didn’t lie. I was 23, getting closer and closer to graduating, and now life had decided to throw me another cancer hurdle in the form of a recurrence in my neck, next to (or possibly wrapped around) my carotid artery...but I was determined to overcome it.

The first step I took was emailing my advisor, Dr. Nachtmann, in the Industrial Engineering department and letting her know what had happened. She immediately took action and started emailing & contacting the people who needed to know, while also getting a petition approved for me to be able to take classes online (I was adamant that I wanted to keep moving forward even through chemo - little did I know, the chemo would take a lot more out of me than I expected, and I’d be too weak to keep up with the classes). My favorite professor, Dr. Sullivan, who had helped me through the toughest part of my recovery the year prior when I had shingles and was getting behind in his class, immediately contacted me to tell me how upset he was after hearing the news. He had always kept in touch with me, even after I wasn’t in his class anymore, to see how I was doing and to make sure I didn’t need anything. His help and support, as well as that of my advisor, was key in helping me push through the worst, lowest, hardest parts of my upcoming treatment. Anytime I was in too much pain to talk, or walk, or even breathe, I would think of their words and remember I was being welcomed back with open arms. It never failed to make me smile. I was also lucky enough to work with a couple of wonderful ladies who cared about me enough to start a fundraiser, and organized it so that I would get some money to help with the bills and expenses I’d have while in Houston.

When I started chemo, I was able to stay at home and get my treatment locally. I would either go into the office or work from home, and go to chemo every Tuesday. Thankfully, I only had my “big chemo”

every three weeks, which consisted of three different chemo drugs that would knock me off my feet and onto the bed or couch. It became routine for me to go to my mom’s house and stay with her every three weeks during big chemo week, ‘cause it would take almost exactly a week every time for me to start feeling better and be able to get on my feet.

I decided to start a blog when I was told about the recurrence. I went online, found a website dedicated to helping cancer patients or people with illnesses make their own blog page, and went to town typing up my feelings and posting them online for the world to see. It gave me some control back over my life, seeing that I could express my feelings and talk about what was happening to me, and people would comment on it with their support! My blog was shared around the office, with my SPOHNC group, with the Industrial Engineering department, and with anyone and everyone that my loved ones wanted to share it with. I was also amazed when I was approached by the wonderful ladies at SPOHNC, asking me to be one of the young adults who will lead the upcoming Young Survivor’s Forum. It was humbling to know that I was being considered for such an honor of being one of the people that starts something that can, and *will* help so many adolescent & young adult (AYA) oral, head, and neck cancer survivors out there. It always makes me feel so great when people, especially an organization like SPOHNC, recognizes the need for more AYA resources, and the unique concerns and hurdles we tend to have to face with a cancer diagnosis. Issues such as dating, fertility, terminal cancers, body image, and many more are so vastly different than pediatric or adult patients that it is oftentimes extremely hard to find support and help, even in our day and age of modern technology.

When the date of my surgery started getting closer, I prepared myself for two long months of being in a new place, environment, and around people I didn’t know well. I emailed my professors and told them a farewell and that I’d see them again, and when I came back, I’d be the only student happy to be back in school. I went to campus and I was surprised when Dr. Sullivan came up with a huge grin on his face and handed me an envelope with well-wishes and get-well cards inside, as well as...donations. He had started his own

fundraiser within the Industrial Engineering Department, and had gotten some donations to help me with any expenses I’d have during treatment. I thanked him profusely and was almost at a loss for words in what to say. When I got in my car, I started crying tears of joy because I felt so loved and cared for by the people that knew I was going through the fight of my life.

When my surgery date finally arrived on April 21st, I had prepared a living will and wrote in it any and all wishes that I had for my family, friends, my dog, and my possessions. I wrote who got what, what I wanted if I didn’t come out of surgery alive, whether I wanted a funeral or a celebration of life, and all of those things, and I can honestly say that was one of the best things I have ever done for myself in my life.

In May I got a feeding tube in my stomach after having one in my nose for about a month. The tube was so long that when extended, it went down past my knees and I could swear that it was three feet long. I wrote a long post in my blog about how I had a lot of fun with the tube, chasing my dog around the apartment that a Hispanic church was letting us stay in during my treatment, and making my mom almost fall over laughing when I stepped out of the shower once, tube rolled up underneath the towel covering my body, and when she turned around I opened the towel and the tube unrolled itself and fell past my knees, swinging back and forth while I danced. I tried to make the best out of my situation, since I’ve never been the type of person who saw any point in complaining without doing something to better or fix the problem, or who only saw the bad side of things. I am someone who looks for the silver lining in things, and I did that even when I was told I might have a feeding tube for the rest of my life. I was mad about it, of course, but I don’t think I was ever sad during my treatment. All my energy was spent being so angry at my cancer that I just wanted to do whatever was necessary to get rid of it. I wanted to kick that cancer’s butt so hard it would be *afraid* to come back.

While in Houston I had more chemo, 20 rounds of IMRT radiation, radiation *during* surgery while open on the table, and a skin flap where muscle was taken from my left leg and put into the right side of my neck where the tumor had been. I, of course, took Thane, my co-survivor doggie with me, and my

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family alternated about every couple of weeks being with me and going home. I can call Thane my co-survivor because not only was he with me during treatment the second time around, but there is one incident I distinctly remember where I was in so much pain I couldn't sit up, much less talk, but I couldn't sleep



and needed medicine to help. My dad was knocked out on the bed next to mine, and Thane, when seeing me in distress, jumped over to my dad's bed and pawed at him and licked his face to wake him up. It worked! My dad woke up and immediately got up

and rushed over to me when he saw my face. If it hadn't been for Thane, I'm not sure how long it would've taken me to get my dad's help.

Once I was done, I came back to my apartment with my fur-child and, after a couple of months of seeing how sad he seemed being alone while I was at work, I decided to take him with me to the local Humane Society and see if there was any other small dog there that he would get along with...and thus, Tali joined

our family. She was such a tiny puppy at twelve weeks that as soon as I picked her up, she fell asleep on my shoulder, and she almost fit nose to butt on it, too! I decided to try and see if they got along, so I took her home with me, and it was an instant connection for the three of us. Now she is over a year old and twice Thane's size and weight, but still an ever curious and joyful puppy. Thane is much happier with her around, and they both play together quite a few times every day, never seeming to tire of it.

My saga continued when this January I reconnected with an old friend from high school, and we instantly hit it off. We both realized that we'd had feelings for each other back then, and could now act on them...so we did. It takes a strong person to date a cancer survivor, especially since I know from experience that there are people who will just suddenly stop talking to you as soon as they find out you've had cancer. Some people treat you like you're contagious, and others think that all you do is cry and be depressed that you've been ill. I am proud to say I am a shining example of the complete opposite of that stereotype. I love to laugh, to make

people laugh, to spend time with my friends and family, to walk my dogs, to get to know people, not to mention various hobbies (one of which includes writing!). Because of this, I was able to reconnect with a guy who is willing to take me as I am, all of my cancer "baggage," and who doesn't care that I have to eat through a tube. In fact, he *helps* me get the IV pole set up, the gravity bag and food ready, and even my medicines any time he is with me. He is the kind of guy who will do anything to bring a smile to my face, even if that means sending me flowers for no reason. He loves me despite the fact that I've had cancer and have been through two rounds of hell. He doesn't see "Rita the Cancer Patient," he sees "Rita the Engineer, the Video-Game Playing Transformers Nerd, the Pet Parent," and all the other different pieces that make me who I am. Cancer doesn't define me, and I will not let it take any more pieces of me than it already has. I am a big, colorful puzzle, and any of the pieces that cancer may have taken are being filled with love, memories, loved ones, and most importantly: Me.

~ Rita Avila - ravila@email.uark.edu

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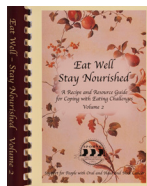
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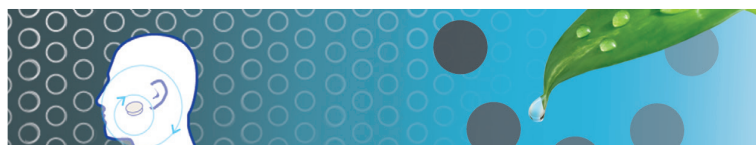
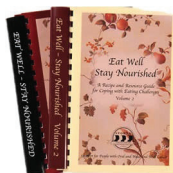
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Laryngeal Cancer Reconstruction

Craig Zalvan, MD

Cancer of the larynx is highly curable when a patient presents with an early stage lesion. Because the voice box is so sensitive to any change, even very small cancers typically present with a change in voice, trouble swallowing, discomfort in the throat or pain in the ear. This should be investigated with a small scope placed through the nose to evaluate the entire voice box and throat, especially if the patient has a history of smoking.

A Laryngologist is a physician who specializes in disorders of the throat and can detect very early cancers of the voice box with specialized equipment called stroboscopy. Once cancer of the voice box is diagnosed, treatment is based primarily on the stage and location of the cancer. Cancer of the voice box is unique in that the staging is based not on size but rather on mobility of the vocal folds and extension of the growth into different areas of the voice box. Generally speaking, the area of the voice box above and below the vocal folds tends to be associated with more aggressive cancers that spread to the neck. These cancers are often treated more aggressively with either surgery and radiation therapy or a combination of chemotherapy and radiation therapy. Reconstruction is typically performed during the initial surgical resection if that treatment is chosen.

Cancer of the vocal cords typically presenting in the early stages can be treated with surgery or radiation therapy alone. The survival rate for radiation therapy and surgical therapy are almost equal. Radiation therapy has the unfortunate side effects of swallowing difficulties, inability to use radiation therapy again if another cancer occurs, and stiffness and irritation of the skin and other structures of the neck. I use a KTP laser to treat the majority of early cancers of the vocal cords. The properties of this laser allow for complete removal of the cancer with minimal removal of normal tissue. This technique provides an excellent outcome with regard to vocal quality with minimal swallowing difficulty and preserves the use of radiation therapy if needed in the future.

Fortunately many of these cancer treatments are successful but can come with a price: hoarseness, trouble swallowing and

airway compromise with difficulty breathing. These side effects of treatment may be related to the actual stage of the tumor itself: early cancers have excellent long term survival and limited side effects whereas more advanced cancers have a poorer long term prognosis and have significantly more side effects from the treatments. In the normal voice box, the vocal folds open to breathe and close together to vibrate as air moves past them thus creating sound that is transformed into understandable voice. Voice problems in cancers of the voice box may be due to two main factors: the vocal cords do not approximate each other and there is air loss from incomplete closure as well as stiffness of the vocal cords; this all results in vocal cord insufficiency.

This incomplete closure of the vocal cords is the primary cause of hoarseness in the majority of patients with early stage laryngeal cancers treated with radiation. This can be due to loss of tissue, underlying scarring, or stiffness of the vocal cord. Radiation therapy can lead to significant scarring and stiffness of the vocal cords which leads to decreased vibration with loss of air while speaking and significant decrease in voice quality. The first step in intervention with vocal cord insufficiency is conservative measures to address the many factors that contribute to and exacerbate laryngeal function. Hydration and humidification are key to a healthy environment within the voice box. Control of post-nasal drip with salt water irrigations to thin out the normal mucus that is present and remove contaminants and allergens should be undertaken. Control of gastric acid reflux with a more Mediterranean style diet, and restriction of the types of food and drink which cause reflux such as coffee, tea, chocolate, soda, alcohol, and greasy food are helpful.

Voice and swallowing therapy performed by skilled speech pathologists specializing in these disorders can be extremely helpful in improving the vocal quality by limiting muscle tension that might be present, allowing for better efficiency of breathing, and increasing vocal strength. Swallowing exercises can help especially in patients who have swallowing problems following treatment with radiation therapy.

If conservative measures and speech therapy has not improved the vocal quality or if swallowing problems persist, intervention with procedures can be performed. A highly effective procedure is termed an injection laryngoplasty. This procedure essentially “implants” material into the space next to the vocal fold and pushes the vocal fold toward the midline. This can close the gap between the stiffened vocal cords and increase the pressure below the vocal cords, which in turn can improve vibration and vocal quality. A variety of materials can be used for this procedure. Some materials are short term and can be used as a test to see if the procedure can be helpful. Other materials are longer term and can last from months to years. This procedure can be performed in the outpatient office setting with topical anesthesia, without sedation. This procedure can also be performed in the operating room with anesthesia, though typically without a breathing tube.

Another option is an open surgical procedure called a thyroplasty. This procedure is performed in the operating room under sedation and requires a small incision in the neck over the Adam’s apple. A small hole is drilled into the cartilage of the voice box through which a permanent implant is placed. The implants include Goretex (which is the material I use), silicone, pre-formed implants, and hydroxylapatite. The primary goal of the procedure is to push the paralyzed vocal fold or the vocal cord with a defect toward the midline effecting better closure to improve the voice and airway protection.

These procedures have the same goal: close the vocal cords gap which can then increase the pressure below the vocal cords allowing them to vibrate with better efficiency. These procedures typically help people with earlier stage laryngeal cancers. In patients who have larger defects from more advanced cancers, reconstruction becomes substantially more challenging, especially if there has been concurrent radiation therapy. For larger soft tissue defects, grafts can be obtained from the buccal (cheek) mucosa and transplanted. Local tissue rearrangement with skin flaps and muscle flaps can be used for larger defects. Finally, free flaps – taking healthy tissue with muscle, bone, and/or skin from other parts of the body to reconstruct

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large defects can be undertaken. Other materials include biocompatible tissue from other animals, cadaveric human preserved skin, and even man-made materials for reconstruction.

In summary, cancer of the vocal cord is typically very treatable with long term survival. Voice and swallowing issues can arise from surgery or radiation therapy of the vocal cords primarily due to stiffness of the vocal cords, or a defect in the vocal cord. Conservative treatment options should first be used as well as voice and swallowing therapy. If these measures are inadequate, injection into the vocal cords can be attempted using a variety of materials. Lastly, local and regional reconstruction can be used in cases amenable to further surgical intervention.

Editors Note: Craig H. Zalvan, MD is a fellowship trained laryngologist and Medical Director at the Institute for Voice and Swallowing Disorders in Sleepy Hollow, NY. He is also an Associate Professor of Otolaryngology at New York Medical College in Valhalla, NY and the Director of Laryngology for ENT Faculty Practice, LLC. He specializes in disorders of voice, swallowing, and chronic cough. He has extensive experience with laryngeal cancer treatment and rehabilitation of head and neck cancer.

First Annual Rick Agee Memorial Skate/Run4SPOHNC

April Awareness Month was truly bittersweet for patients, survivors, family and friends and several healthcare professionals in the Dallas-Forth Worth area of Texas this year. Saturday, April 25th was particularly so, as many gathered in memory of one of



SPOHNC's nearest and dearest friends, Rick Agee. The First Annual Memorial 5K Skate/Fun Run in Memory of Rick Agee took place in Little Elm, Texas, on that day.

It was a glorious morning as participants (and even some pets) gathered to memorialize and honor their friend, Rick. The Agee family, the 5 Dallas area SPOHNC Chapter Support "teams" and SPOHNC Founder, Nancy Leupold, along with Mary Ann Caputo, Executive Director of SPOHNC, came together at the Paloma Creek Amenity

Center for an event that would have made Rick pleased and proud. He was indeed smiling down on everyone that day.

As the sun rose in Little Elm, a group of dedicated volunteers came together to

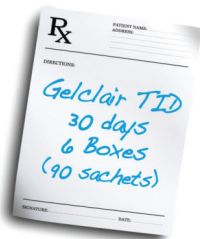
prepare the venue and surrounding grounds for the big day. There was much to do in little time, and



everyone cheerfully took on their volunteer positions and readied for the arrival of in-line skaters, runners, and walkers alike. As Jack Hess' camera captured images from the day, everyone remembered the warm and friendly man whose courage and humility made him so special. Rick's presence was undoubtedly felt by all.

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Close to 200 people attended the family friendly event, which included a free oral cancer screening by Dental Oncology Professionals of North Texas, a table from UT Southwestern Hospital, raffles, 400 flats of beautiful flowering plants were provided for sale, donated by JR Nursery and Floratech nursery, lots of delicious food, music and more. Entertainment was provided by oral cancer survivor, Sara Pray. Registration for the event included a memorial t-shirt, wristband, sport bottle, lapel pin and complimentary lunch for participants in the day's festivities. The net proceeds from this event will be donated to SPOHNC in October of this year, to further the fine work that SPOHNC offers to the oral, head and neck cancer community.

The weekend was filled with good old fashioned Texas warmth and hospitality, as Jack and Mary Ellen Mitchell, who worked tirelessly and spearheaded the

event, hosted SPOHNC friends for the weekend, and treated everyone like family, and not just guests.

SPOHNC would like to extend a heartfelt thank you to all who participated in some way – from volunteers to participants, to sponsors and everyone in between - and especially to Rick's loving and devoted family and his beautiful wife, Lynn.

As a fitting tribute to Rick, following the event, a tree, donated by Rick's "SPOHNC Chicks in New York," has been planted in a nearby park, and a park bench with a plaque, provided by the SPOHNC fund raising event, has been placed, in honor of our dear friend Rick. The park is a place that Rick and Lynn visited frequently, and Lynn, and Rick's family and friends visit the park often, where they can sit on the bench, look at the tree and fondly remember



the man with the Texas twang who made everyone smile. God bless you, Rick. We will always remember you, and miss you.

"Sadness gives depth. Happiness gives height. Sadness gives roots. Happiness gives branches.

Happiness is like a tree going into the sky, and sadness is like the roots going down into the womb of the earth. Both are needed, and the higher a tree goes, the deeper it goes simultaneously. The bigger the tree, the bigger will be its roots. In fact, its always in proportion. That's its balance." ~ Osho



SPOHNC had so much news to share this month that we had to temporarily remove our Chapter page. Our Chapters are up and running. Contact SPOHNC at 1-800-377-0928 for Chapter information.

In Memory of Madelyn Harper Walsh - A Lady of Great Strength

Our hearts are heavy, as we share the very sad news that we have lost a dear and very special member of our SPOHNC family. SPOHNC's Board of Directors, staff and the attendees of the SPOHNC Syosset, NY and Huntersville, NC Chapters mourn the loss of Madelyn Ann Harper Walsh.



Madelyn, known to many of her friends as Lyn, had a long and very devoted history with SPOHNC.

Beginning as an attendee at the SPOHNC Syosset Chapter, immediately following her diagnosis 11 years ago. Madelyn quickly became an integral part of the group, and was instrumental in the success of many of the LI SPOHNC Chapters Taste Events. Her dedication to so many causes was apparent, as friendships and relationships bloomed in Madelyn's life. Her answer was always "yes" to anyone who needed her help, her time, her leadership and devotion. Her involvement in the Long Island community

as an active member of her church and many community groups, including Kilian's Friends, Knights of Columbus and Rotarians, kept her very busy, but she always had time for family and friends, and for SPOHNC. Always up for a friendly gathering, Madelyn and her husband Bill even hosted a SPOHNC Backyard BBQ at their home several years ago.

SPOHNC Syosset Co-Facilitator Alice Steiner shared a very special friendship with Madelyn, having met her 11 years ago when they were both newly diagnosed, and found themselves at the same doctors office, and often for radiation treatments, at the same time. Madelyn was diagnosed just a few short weeks after she and Bill were married, and he continued to be her loving husband, holding her up and supporting her through all that she endured. Her faith and her love for Bill surely kept her attitude positive as she travelled her cancer journey.

After several years as Facilitator of the SPOHNC Syosset Chapter, Madelyn's Long Island SPOHNC family was sad to see her leave, as she and Bill embarked upon a new adventure, moving to Huntersville, NC,

where Madelyn's company had offered her a transfer. She always encouraged visitors to their new home, telling everyone "the door is always open!"

Madelyn and Bill continued their tradition of community involvement, meeting new friends along the way, and of course, Madelyn launched a new SPOHNC Chapter in the town of Huntersville, NC. The group quickly became a close knit family, and has supported one another in ways no one would have ever imagined would be needed. SPOHNC is grateful to the Huntersville, NC SPOHNC Chapter, for their prayers and loving support of Madelyn and Bill.

SPOHNC will miss Madelyn's enthusiasm, her sense of humor, her beautiful smile, and the way she made everyone feel special, all the time. Her warmth, kindness and grace will always be remembered. As Alice shared with SPOHNC recently, "she was one of the most special people I've ever known... a remarkable woman."

From your SPOHNC family, Madelyn, you will remain forever in our hearts, as truly a lady of great strength...



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**Best Wishes
from SPOHNC
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