

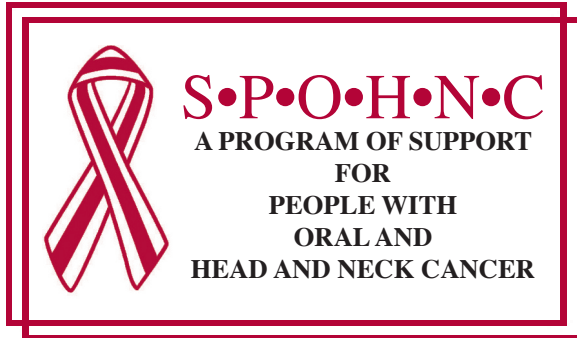
# NEWS FROM S·P·O·H·N·C



VOL. 28 NO. 8

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

MAY 2019



## Proton Therapy Success with Head and Neck Cancer

Steven J. Frank, MD

Imagine a 196-ton, cancer-killing machine that can target a patient's cancer with sub-millimeter precision while sparing nearby healthy tissues and minimizing side effects. In its most simple terms, that's proton therapy.

Proton therapy is an advanced form of radiation treatment that delivers a powerful, highly precise beam of radiation directly to the cancer. Protons enter the body with a low radiation dose, stop at the cancer, match its shape and volume and depth, and deposit the bulk of their energy right at the cancer. The target treatment destroys cancer cells while sparing healthy tissues.



Proton therapy has a major advantage over other forms of treatment when treating vital organs such as the brain, heart, esophagus and lung. It is even more effective when treating complicated cancers of the head and neck to protect vital structures such as the eyes, mouth and

brain. Patients experience fewer side effects and improved quality of life, during and after treatment.

### *Types of cancers treated by proton therapy*

There are many types of cancers of the head and neck. Even benign tumors can cause symptoms or threaten the health and well-being of a patient. Proton Therapy may be used to treat cancers of the:

- Oral cavity
- Oropharynx (tonsil and base of tongue)

- Hypopharynx
- Larynx
- Nasal cavity
- Paranasal sinus
- Periorbital area including medial canthal tumors
- Base of skull including paragangliomas/schwannomas, chordomas, chondrosarcomas, sarcomas, squamous cell carcinoma, adenoid cystic carcinoma
- Parotid gland
- Submandibular gland
- Minor salivary glands
- Unknown primary cancer
- Skin
- Reirradiation for recurrent cancers of the head and neck or new primary malignancies in a radiated field
- Nasopharynx

It is important for Radiation Oncologists to work closely with a skilled multidisciplinary team to provide comprehensive care for patients who have benign or malignant tumors of the head and neck.

### *What to expect*

Multidisciplinary care, is the hallmark feature of the approach to management of the cancer patient. When treating head and neck cancers, a diverse team of oncologists, surgeons, radiation oncologists, dental oncologist, and others with special training are needed to design a customized treatment plan.

The day of your treatment, the radiation therapist positions the patient to deliver the prescribed proton therapy dose accurately. A typical treatment session can take about 15 to 30 minutes each day for a patient with cancer of the head and neck. Most patients can tolerate the treatment and can continue to work and exercise during and immediately after treatment is complete. Proton therapy treatment is usually painless and non-invasive.

### *Side effects from head and neck treatment*

There are different treatment options for patients who have cancer of the head and neck, which can include: surgery, radiation, chemotherapy, or any combination of the three. Each type of treatment can change the way the patient looks, talks, eats or breathes. Therefore, it is important to preserve the patient's quality of life so they can return to their normal activities as soon as possible.

Radiation destroys the cancer cells, but it also destroys healthy cells, which can cause difficult side effects. Patients who receive radiation to the head and neck may experience:

- Altered taste (dysgeusia such as metallic/cardboard)
- Loss of taste (ageusia)

PROTON THERAPY continued on page 2

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- Dry mouth (xerostomia)
- Thick saliva
- Mouth ulcers (mucositis)
- Pain on swallowing (odynophagia)
- Difficulty swallowing (dysphagia)
- Fatigue
- Nausea
- Vomiting
- Constipation (side effect of narcotics for pain management)

Also, patients may experience redness, irritation, swelling or drooping of the skin. However, any side effects that may occur during Proton therapy treatment often disappear fairly quickly once treatment is completed.

With Proton therapy, such side effects are reduced enabling patients to better maintain their weight and hydration. As a result, patients not only achieve successful treatment outcomes but substantially improve their quality of life both during and after cancer treatment.

The use of Proton therapy can help reduce the costs associated with treating these symptoms. This includes costs for:

- Nutrition management (dysgeusia and weight loss)
- Pain management (narcotics)
- Bowel management (constipation)
- Speech and swallowing (dysphagia, odynophagia and aspiration)
- Hospitalization (chemistry and hematology)
- Emergency center (nausea and vomiting)
- Ambulatory center (IV fluids for dehydration)
- Gastroenterology/Interventional Radiology (feeding tube)

One of the key components in the fight against cancer is finding the treatment option that can achieve the best clinical results. In the case of cancer of the head and neck, proton therapy reduces overall toxicity, improves quality of life during and after treatment and increases the long-term survival rate.

Cancer of the oropharynx (OPC) develops in the part of the throat just behind the mouth. OPC cancer in most cases is linked to infection with human papilloma virus (HPV) and it's estimated that nearly 70 percent of OPC cancers are HPV-positive. A study conducted at MD Anderson Cancer Center found that the use of feeding tubes in patients being treated for oropharyngeal carcinoma (OPC) who were treated with intensity modulated proton therapy (IMPT) was decreased by more than 50 percent compared to patients treated with intensity modulated radiation therapy (IMRT). This suggests that proton therapy may offer vital quality of life benefits for patients with cancer occurring at the back of the throat. Additionally, the toxicity levels in OPC patients treated with IMPT are much lower than those treated with IMRT.

IMPT is especially well-suited for patients with the most complex cancers of the head and neck, by precisely painting the protons onto the cancer layer by layer. In this way, the treatment

PROTON THERAPY continued on page 3

PROTON THERAPY continued from page 2

team can confine the majority of the cancer-damaging energy to target areas and work to protect normal structures such as the oral cavity and brainstem.

***Proton therapy technology***

Proton therapy has evolved and developed in a way that has not been seen before. The development of technology has been very exciting because it opens new doors that allow us to treat in a similar fashion that we are expected to treat with any other forms of radiation.

With a proton beam just millimeters wide, the advanced forms of proton therapy combine precision and effectiveness, offering unmatched ability to treat a patient's cancer and minimizing the effect on a patient's quality of life – during and after treatment. Proton therapy is reliant upon complex treatment planning systems and an intricate number of magnets to properly aim a narrow proton beam and essentially “paint” a radiation dose layer by layer.

Passive scattering was considered standard of care for proton beam delivery. In 2010, proton beam with active scanning became standard of care. By 2012, we were then able to do intensity modulated proton therapy (IMPT) which is the most advanced form of proton therapy delivery that allows us to treat disease sites that we were unable to do previously.

Intensity modulated proton therapy (IMPT) is best used to deliver a potent and precise dose of protons to complex or concave-shaped tumors that may be adjacent to the spinal cord or embedded into the head and neck or skull base, including nasal and sinus cavities, oral cavity, salivary glands, tongue, tonsils, and larynx. Now with the advanced form of treatment delivery proton therapy can be used in every disease site. It is a very exciting time.

We offer innovative clinical trials, which are research studies in which patients volunteer to take part. Currently, we have approximately seven open clinical trials for head and neck cancers including brain tumors. The different trials are studying the effect of higher dosages effectiveness, reirradiation, quality of life, and more. We also participate in collaborative clinical trials that span the globe.

Through our clinical trials we are developing new technologies to benefit more

people with cancer. Our research base focus is defining the role of proton therapy in every disease site.

One of the things that make our center unique is that over the last years we have put out a great deal of research and publications in proton therapy, which is truly defining us as a leader in the academic radiation oncology space. With our dedicated and passionate physics team we have published more than 450 articles on the physics and outcomes of proton therapy, which have propelled the expansion of this type of radiation. In 2017, proton therapy became a standard of care radiation treatment option in the NCCN head and neck guidelines.

Our team's breakthrough pencil-like beam technology and intensity modulated proton therapy (IMPT) have allowed us to treat a variety of cancers including brain, head and neck, prostate, lymphoma, lung and childhood tumors.

***The future of treatment of cancers of the head and neck***

Cancers of the head and neck can be complex and must be treated delicately, yet aggressively for effectiveness. With Proton therapy technology, the high doses of radiation necessary for treatment of the cancer can be delivered, while protecting nearby normal structures to prevent neurological deficits, intellectual impairment, blindness, and other side effects. These are some of the reasons that proton therapy has become an important tool in the treatment of cancer.

Proton therapy is the future of treatment of cancer of the head and neck. Today, there are 25 proton therapy centers operating in the United States and 10 currently under construction. Moreover, Proton therapy has become an important cancer therapy worldwide. Even countries with limited means are developing Proton therapy centers. There are 49 centers in operation worldwide including China, Japan, Italy, and Germany.

Research has demonstrated that proton therapy can maximize disease control, minimize both early and late side effects, preserve organ function and quality of life, and minimize extraneous radiation dose to the patient. As part of our commitment to the advancement of science, clinical practice, and patient outcomes, we continuously search for opportunities to communicate the

value of Proton therapy to the world.

*Editors Note: Dr. Frank is an endowed tenured professor of Radiation Oncology at The University of Texas MD Anderson Cancer Center, the Medical Director of MD Anderson's Proton Therapy Center, and leader of both the Proton Therapy Program for head and neck cancer and the Prostate Brachytherapy Program. Dr. Frank also serves the Division as Director of Advanced Technologies in Radiation Oncology; he is amongst the first, if not the first, to use Intensity-Modulated Proton Therapy (IMPT) to treat head and neck tumors.*

*Dr. Frank is the Principal Investigator of an NIH/NCI-sponsored Phase II/III randomized trial in oropharyngeal cancer that compares outcomes after chemoradiation given by IMRT versus IMPT. His other major clinical research accomplishment includes the successful accrual of 300 patients in a Phase II protocol for prostate cancer. Dr. Frank's expertise in MRI radiotherapy has led to the development and FDA approval of a novel positive-contrast implantable marker for use in MRI-guided prostate brachytherapy.*

*As founder of the company, C4 Imaging, Dr. Frank has developed the MRI marker technology at MD Anderson, currently holds 31 national and international patents and has continued MRI-Assisted Radiosurgery (MARS) at MD Anderson for the treatment of prostate cancer. He has funding from the NIH, the Prostate Cancer Foundation, the Texas Ignition Fund, Hitachi and MD Anderson, and he has also raised three rounds of private equity financing to advance C4 technology.*

*Dr. Frank's expertise in prostate brachytherapy is reflected by his service as past President and Chairman of the Board of the American Brachytherapy Society. Dr. Frank's expertise in head and neck cancer has been acknowledged by his chairing the American Board of Radiology's Oral Examinations Program for head and neck cancer.*

**“SPOHNC  
is a wonderful organization and  
worthy of national note.”**

**~ Mitch S.**

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## CHAPTER FACILITATOR NEWS

### SPOHNC REPRESENTED AT ORAL, HEAD & NECK CANCER WORKSHOP

*Contributed by Valerie Targia, SPOHNC San Diego, CA Chapter Facilitator*

On Saturday, April 27, the Head & Neck Cancer Department of one of our local hospitals, Sharp Memorial, held a community event highlighting oral, head and neck cancer awareness.

I was invited to exhibit, and set up a table representing SPOHNC. We were in an ideal location near the lecture room, and everyone had to pass our table going in and coming out.

There were 40 or 50 attendees. Not as many as they had hoped, but oral, head and neck cancer is not a very common cancer. Six professionals presented—two oncology surgeons, a radiologist, a patient navigator, a nurse practitioner, and a dietician. They spoke on a full range of topics relevant to oral, head and neck cancer.



Some of the subjects covered included treatment options, possible symptoms of treatments, surgical procedures and recovery times, the latest radiology techniques, the different roles of a nurse navigator, and a nurse practitioner, the importance of good nutrition and diet through cancer treatments and beyond.

The speakers were followed by a Q&A session involving audience participation. It was an extremely worthwhile event, covering a wealth of information, and it provided excellent exposure for SPOHNC to medical oncology professionals, and the public.

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## HEAD AND NECK CANCER NEWS

Stanford Medicine, the Stanford Cancer Center and the Stanford Otolaryngology Clinic held its third annual day long Head and Neck Cancer Patient and Caregiver Education Symposium on April 6<sup>th</sup> on the Stanford University Campus.

The Symposium drew over 150 people including physicians and other medical and health professionals, head and neck cancer patients and survivors, caregivers and others interested and involved in this area of cancer diagnosis, treatment and recovery. Breakfast and a keynote address were followed by a Radiation Oncologist that discussed surgery, radiation, chemotherapy and newer enhancements in the treatment of head and neck cancer. A panel followed with two medical professionals and two survivors that highlighted the difficult and highly individualized process, both physically and psychologically, that head and neck cancer patients go through. A physician then talked about treating oropharyngeal cancer, including improved techniques such as robotic surgery and others that improve recovery speed.

Following a networking coffee break was a presentation by a physician specializing

in thyroid gland cancer, including thyroid gland functions, hypo and hyperthyroid gland conditions and the different forms of thyroid gland cancer treatments. Lunch was preceded by a panel where surgeons answered questions about the types of surgery available for treating head and neck cancers and what to expect before, during and after surgery.

The Symposiums afternoon program began with a Pain Panel of professionals, with the major message being that intelligent use of pain management drugs can be valuable to many patients during the treatment and recovery process. A physician then talked about multiples types of Cannabis and their use in helping some patients in the recovery process. Another professional gave a short talk about the importance of food and eating, including the social aspect of eating as a patient moves through the often tedious process of recovery.

A Survivorship Panel, consisting of a head and neck cancer survivor and four professionals, discussed the importance of food choices, psychological disorders and the value of communications between

patients and their caregivers and appropriate professionals available to the patients. The Symposium concluded with a panel of two program presenters and a survivor that talked about “New Horizons” in the diagnosis and treatment of head and neck cancer.

*Editor's Note: The above was provided by Jerry Young. Mr. Young was diagnosed with vocal chord cancer in 2006, underwent a successful partial laryngectomy at Stanford in 2007, has been a member of SPOHNC for 10 years and has been an active participant in the Stanford, CA SPOHNC Chapter support group during this period.*



*photo courtesy of PJ Jordan. NSVN Volunteer*

## Join SPOHNC to Find Inspiration and Hope Through the Power of Storytelling with the Newly Launched Program “With Love, Me”

This year, we’re continuing our partnership with Merck and *Your Cancer Game Plan* to help those impacted by cancer with the launch of a new program – *With Love, Me*. The new initiative features a series of heartfelt letters on [www.WithLoveMe.com](http://www.WithLoveMe.com) written by caregivers and cancer survivors to their newly diagnosed selves and other caregivers touching upon what they wish they had known when they were first diagnosed/providing care. Your Cancer Game Plan also continues to feature inspiring videos focusing on Emotion, Communication and Nutrition, featuring SPOHNC’s family members Tom and Maria Folchetti, and



Dennis Staropoli. Visit [yourcancergameplan.com](http://yourcancergameplan.com) to hear their stories.

There’s great power in sharing stories, and when it comes to facing cancer, patients and caregivers have found hearing from others affected by cancer may help. The website features a gallery of patient and caregiver letters where people can read, view and share stories from others who may have walked in their shoes. Learning what it’s like to be a patient or caregiver through another’s journey may help alleviate feelings of fear, anger or sadness and help prepare for what can oftentimes be a daunting road



ahead. Most importantly, it can serve as a good reminder that you are not alone.

Please join us by visiting [www.](http://www.WithLoveMe.com)

[WithLoveMe.com](http://www.WithLoveMe.com) to read and view personal letters from people impacted by cancer, become inspired and learn more about how to take an active role in developing a “game plan” to address the emotional, health and communication challenges of a cancer journey.

Visit today and start sharing your own #WithLoveMe message because your cancer story may help others. As always, thank you for your ongoing support of SPOHNC.

### SPOHNC is Celebrating You!

Happy Birthday to SPOHNC’s “Iron Man”...Frank Marcovitz! Frank celebrated his birthday on May 16th.

If ever there was a man with determination and a zest for life, it’s Frank. Frank has been an integral part of our Syosset, NY SPOHNC Chapter Support group since his diagnosis and treatment in 2010.



lot of ice cream! If we could share some of his birthday celebration videos, you’d see Frank boogieing and twirling all over the dance floor to his favorite band The Electric Dudes. Wow!

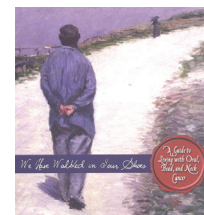
Our friend has been through a lot, and just keeps going – like the Energizer bunny! Sometimes we wonder how his beautiful wife, Carrie, keeps up with him.

Frank, your SPOHNC family wishes you all the best for a year full of joy, laughter, love and lots of all that you enjoy. Happy, happy birthday!!



Lover of life, dancing, ice skating, volleyball, and especially a lover of food – Frank never lets his periodic throat dilations get in the way of his “inner foodie.” Posts on Facebook clearly show that Frank enjoys his many food groups – especially ice cream! Of course, with all the dancing he does, he can enjoy a

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## HEAD AND NECK CANCER NEWS

### *Remedy for painful jaw disease*

April 11, 2019 - University of Southern California - USC researchers and collaborators report a breakthrough to prevent damage to the jaw, a side effect suffered by some people undergoing treatment for cancer or osteoporosis.

The newly published research is an important step toward a cure for osteonecrosis of the jaw, which is a rare side effect caused by drugs commonly used to combat bone loss. It causes severe and persistent inflammation leading to loss of bone from the jaw and has no effective prevention or cure. The risk, though small, deters people from taking drugs needed to fight bone cancer or prevent fractures due to loss of bone density.

USC scientist Charles McKenna said the successful animal experiment, conducted by researchers at USC and UCLA, raises hope that physicians could adapt the new method to treat the condition in people.

“This is a condition that has been excruciatingly painful and difficult to treat for more than a decade,” said McKenna, a professor of chemistry in the USC Dornsife College of Letters, Arts and Sciences and adjunct professor of pharmacology and pharmaceutical sciences in the USC School of Pharmacy. “We think our new approach may provide hope for the future,” he said.

The new published findings appear in *Bone*. The authors are affiliated with the USC Center for Drug Discovery and Development at the Michelson Center for Convergent Bioscience, the UCLA School of Dentistry and a Pasadena-based startup biotech company, BioVinc LLC.

For years, physicians have prescribed a class of drugs called bisphosphonates (BPs) for metastatic bone cancer patients and to maintain bone density in osteoporosis patients. BPs include a range of compounds that share a remarkable ability to stick to bone like Velcro.

But when used in high doses in the cancer clinic, BP drugs sometimes have a terrible side effect causing necrosis in the jaw. The problem often occurs after a tooth is removed, the gap doesn't heal and the jaw begins to deteriorate.

Although the condition is very rare at the lower BP doses used to combat

osteoporosis, many patients are avoiding the drugs altogether for fear of the side effects. The risk is low as the National Osteoporosis Foundation estimates incidence of osteonecrosis of the jaw due to BP used to treat osteoporosis to be between 1 in 10,000 and 1 in 100,000 people annually. Risk has been estimated to be much higher, about 3 percent of patients, at the BP dose used to treat cancer, McKenna said.

Nonetheless, more and more osteoporosis patients are willing to take their chances with the disease rather than risk the side effects. Surveys have shown the recent trend in reduced hip fractures among post-menopausal women may be reversing due to BP drug aversion.

“The fear factor of this condition has led to severe underuse of bisphosphonates for osteoporosis so much so that we're seeing a rise in hip fractures in elderly people, aversion to bisphosphonates in oncology clinics and liability concerns in the dental office,” McKenna said.

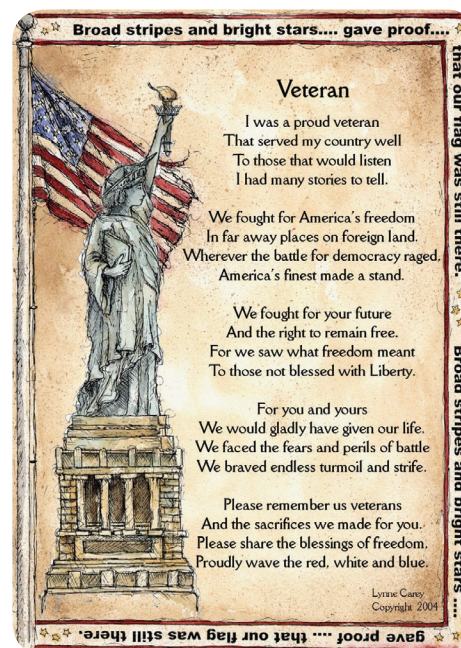
To solve the problem, McKenna devised an elegant solution. The research team used a different BP compound, an inactive compound that could be used locally in the mouth to push the BP drug from the jawbone while leaving undisturbed the useful drug in the rest of the skeleton.

Said McKenna: “Think of it as a way to fight fire with fire.”

The scientists involved in the study used mice to test different BPs attached to fluorescent dyes. One color label coded the BP zoledronate, which is administered systemically to treat osteoporosis and cancer, while a different color labeled “rescue BP” coded a BP compound with similar bone affinity, but no biological activity. The researchers discovered that rescue BP injected into the jaw removed most of the BP drug causing the jaw bone tissue damage, clearing the way for the animal's natural healing process to repair the extraction site.

The new technique isn't ready for clinical use in humans yet. McKenna said BioVinc, which provided funding for the study via a National Institutes of Health small business research grant, will be responsible for advancing the treatment to commercial

clinical use. Several of the authors of the study disclose a financial interest in BioVinc, a company specializing in “bone targeted therapeutics and diagnostics.” McKenna is the company's academic founder.



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

**Shrimp Risotto with Peas (from Volume Two)**

- 1 lb. medium shrimp
- 3 Tbsp extra virgin olive oil
- Coarse sea salt and freshly ground pepper to taste
- 3 shallots, chopped
- 1 Tbsp. unsalted butter
- 1 ½ c. Arborio rice
- ½ c. dry white wine
- 6 c. boiling fish or chicken stock
- 1 Tbsp. mint, finely chopped
- ½ c. basil, snipped with fine scissors
- 2 Tbsp. parsley, minced
- 1 clove garlic, minced
- 1 c. peas, slightly cooked



Peel shrimp and put in a bowl with 2 Tbsp. olive oil, salt and pepper. Toss and marinate at room temperature for 30 minutes. Soften shallots in garlic with butter. Add the rice and cook, stirring for a minute or two until grains absorb butter and turn opaque. Add the wine, bringing to boil to evaporate alcohol. When the wine has been absorbed, start adding the fish or chicken stock, half a cup at a time, and season to taste with salt and pepper. Add the mint, basil and parsley. Turn down the heat and continue adding stock, ½ cup at a time, to the rice and stirring. Continue until rice has absorbed nearly all the liquid. Rice is done when creamy but al dente. Meanwhile, heat remaining oil in separate skillet and saute shrimp for a minute or two. Season with salt and pepper and remove from heat. Add shrimp and peas to the rice. Cook for an additional minute or two to combine. *Serves 4. 592 calories/serving.*

~ Mary C., NY

**Strawberry Crush (from Volume One)**

- 2 c. frozen strawberries
- ½ c. crushed pineapple
- ½ c. water
- ½ medium banana
- 6 tbsp. sugar
- ¼ c. lemon juice
- 2 Tbsp. honey



Process all ingredients in a blender until smooth. *Yields 3 – 8 oz. servings. 221 calories/serving.*

~ Denise W., TX



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## Time for Sharing... The Newsletter That Saved a Life

*Or how a 49-page monthly bulletin for Upper East Siders helped one resident detect, deter and defeat a deadly disease*

BY DOUGLAS FEIDEN - DEC 24, 2018



Kathleen Steed speaks to New York City Council Member Ben Kallos at his recent holiday party for constituents — about how his community newsletter gave her a new lease on life. Photo Courtesy of Ben Kallos' office

*“This is one story I will not be forgetting anytime soon.”*

*~ New York City Council Member  
Ben Kallos*

The 10 scariest words in the English language, Ronald Reagan used to joke, are these: “I’m from the government, and I’m here to help you.”

Kathleen L. Steed embraces a very different world view. Officialdom, she believes, can offer comfort, company, support and holiday cheer. And every once in a while, it can even rescue you from mortal peril.

“The word ‘miracle’ is overused and overworked,” said the 73-year-old Yorkville woman, a retired private investigator and hospital fundraiser. “But this really is a story about a miracle,” she added.

It surfaced on Dec. 13 at the annual holiday party of Upper East Side City Council Member Ben Kallos as some 70-plus constituents mingled in his district office on East 93rd Street.

Over baked ziti from the Italian Village Pizza on First Avenue and gallons of apple cider and other nonalcoholic beverages, Steed buttonholed Josh Jamieson, the communications director for Council District 5.

“Your newsletter saved my life,” she

said simply. Jamieson said he was stunned. Thus began a conversation between a pair of newsletter aficionados.

Jamieson has worked for Kallos for nearly three years, and his duties include writing, editing and curating most of the document, which reaches thousands of constituents online and in a hefty print edition that can range from 30 to 50 pages.

It’s so comprehensive and labor-intensive that he’s regularly on the receiving end of good-natured ribbing from Kallos and Jesse Townsen, his chief of staff, over both the newsletter’s length and its encyclopedic scope.

A recent issue, for instance, was chockablock full with listings for UES events, lectures, exhibits, book groups, support groups, writing circles, yoga workshops, dance rehearsals, ballet workshops, exercise classes, cooking classes, legal clinics, medical services and homeless services.

Not to mention the screenings of “Casablanca,” symposium about the 1830s, drag queen story hours and discussions of the U-boat attacks on allied shipping in the North Atlantic during World War II.

Steed, who has lived in the same rent-stabilized, walk-up apartment on Third Avenue since 1977, is every elected official’s dream: She’s a self-professed “information junkie” who actually reads all their newsletters. Voraciously.

As an active senior who lives alone and likes to keep busy, she can often be found at gatherings, parties and other activities for the elderly that she’s spotted in the newsletters of Kallos, state Senator Liz Krueger, state Assembly Member Rebecca Seawright and U.S. Rep. Carolyn Maloney, as well as nonprofits like the Lenox Hill Neighborhood Association and Health Advocates for Older People.

Of those six community newsletters, Kallos’ is by far the longest, while Krueger’s is a close second, Steed said. “Sometimes,” she confessed, “I don’t read it all the way through ... I just scan it!”

Nonetheless, she made it to page 46 of the 49-page July newsletter and focused on an event listing: “In honor of World Head and Neck Cancer Day,” it said, “please join us for free head and neck cancer screenings

offered through Memorial Sloan Kettering Cancer Center.”

### GAULOISES NOT AS ROMANTIC AS THEY SOUND

Steed had started smoking as a 15-year-old growing up on a farm in Colorado in 1960. She kept at it when she moved to Haight-Ashbury after high school. And when she arrived by bus in Manhattan in 1966.

Gauloises, the French cigarette, was her preferred brand, and hers was a 2.5 pack-a-day habit, she said. It continued during her career in book publishing at Pantheon in the 1970s and in her investigative work with private firms in the early 1980s.

After 25 years of 50 cigarettes a day, Steed finally quit in 1985, and she hasn’t smoked in 33 years.

Still, she feared the damage had been done. So on July 27, she headed uptown to the Ralph Lauren Center for Cancer on Madison Avenue at East 124th Street in Harlem for the free screening — a 10-minute exam to check for a type of cancer that can afflict the nasal passages, mouth, throat or voice box of smokers.

In short order, Dr. Laura Wang found a suspicious lesion on Steed’s upper gum, and referred her to Dr. Jennifer Cracchiolo, a surgeon at Memorial Sloan Kettering, who conducted a biopsy that found she had cancer of the gum tissue on the right upper jaw.

Oral cancer makes up only three percent of new cancer cases, and it’s often overlooked, even by dentists, because of its location and initial innocuous appearance, which makes it seem more like a nuisance than a potential lethal malady.

In many cases, it will have spread to the lymph nodes by the time it’s detected, a Stage 2 condition in which 35 percent of patients die after five years, or metastasized into a Stage 3 condition, which is even more fatal.

Steed was one of the lucky ones. Thanks to the screening, and the newsletter, her cancer had been discovered at an early stage.

Six weeks later, on Sept. 10, she went into surgery at Memorial to remove her maxillary, or upper jaw, and a part of her palate. Doctors have since deemed her

continued on page 9



continued from page 8

completely cancer-free. “Kathleen sounded grateful and determined and full of life,” Jamieson said as he recalled their encounter.

Steed said she now has three goals: “To educate people about oral cancer, to emphasize the importance of attending as many free health screenings as possible — and to note how newsletters from elected officials can change lives.”

And she added, “If anyone ever questions the necessity of having 49 pages of listings, please remember that one of those listings saved my life.”

Kallos said he was always curious about the utility of his newsletter and whether it could be a tad too long, a subject he enjoys raising with Jamieson.

“Some might argue that less can be more,” he said. “But this is the argument against a shorter work product.”

“I am incredibly happy Ms. Steed is here to tell her story,” Kallos added. “This is one story, and one holiday party, that I will not be forgetting anytime soon.” *Reprinted from OUR TOWN*

### *Ten Tips for Holiday Travel*

Whether for vacation, work or to spend time with distant friends and relatives, for cancer patients any travel requires planning.

1. Notify your provider in advance
2. Plan ahead for your destination
3. Make sure you have enough medical supplies
4. If you are flying, contact your airline
5. Reduce your risk of infection with diligent handwashing
6. Have a letter from your physician about your condition
7. Check immunization needs for your destination
8. If you experience symptoms seek medical attention right away
9. Protect yourself from the sun and stay hydrated.
10. Get plenty of rest and go at your own pace

## **SURVIVOR NEWS**

### **Speech Difficulties After Stage IV Oral Cancer**

#### *Christine's Story*

As a Stage IV oral cancer survivor, I am very passionate about spreading awareness. Oral, head and neck cancers are profoundly different than other cancers in that they limit one's ability to swallow, eat and talk. These limitations are more pronounced after surgery and radiation treatments. Sadly, at times, the limitations can be permanent.

After my 14-hour surgery on February 21, 2012, my mouth and tongue were so swollen that I could not breathe on my own, so a trach was inserted during surgery to assist in my breathing.

I also could not speak. My tongue was so swollen that I could not close my mouth. I was only able to interact with people by writing on a whiteboard or dry erase board, and by texting on my cell phone. It was difficult when I needed a nurse because when I would buzz for one, they would ask what I needed and of course, I could not talk. I would buzz again and again until a nurse entered my room. The sweet nurses were more than likely becoming annoyed with me at the time.

When I first regained the ability to speak, I sounded as if my mouth was full of marbles. Another comparison of my speech was that I sounded as if my entire mouth was shot full of Novocain. It was extremely difficult to speak coherently so people could understand me. Upon returning home after my hospital stay, I worked with a speech therapist until my insurance company stopped paying, which was about three sessions. My therapist left a sheet with exercises for me to do. Besides doing the exercises, I would try reading to my grandson and singing to songs. Believe me, the singing was not pretty, but I kept trying.

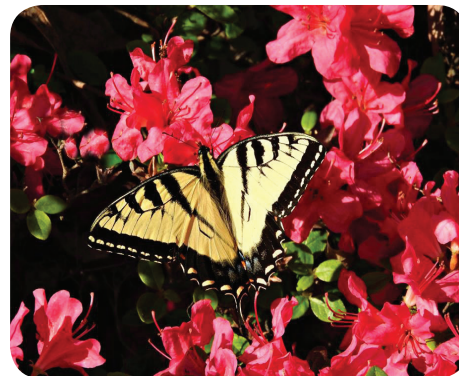
Currently, when speaking at times, I tend to mispronounce my 't' and 's'

sounds if I talk quickly. However last May 30th, I was the keynote speaker at The Hershey Lodge in Hershey, PA for Penn State Cancer Institute's Surviving & Thriving Cancer Survivorship Celebration, and plan on doing more speaking. I am blessed that I can talk to help raise awareness, although it may not be perfect at times. I couldn't speak for a length of time, now you can't get me to shut up.

Never, ever give up! Things will get better with time. Think only positive thoughts and have faith. Believe in yourself that you will conquer this bump in the road. Also, don't live your life with "what if" cancer comes back. Live for the moment and make the most of everyday. Tomorrow is a new day so move forward. Never, ever give up. You can do this. I know you can.

I thank God and Roswell Park Comprehensive Cancer Center for my ability to speak. Spend one day with Roswell. I did and then some, because Roswell rocks!

*Editor's Note: Christine shared her story on SPOHNC's closed Facebook group and gave SPOHNC permission to share her story in our newsletter. If you'd like to share your story, contact SPOHNC at [info@spohnc.org](mailto:info@spohnc.org) or 1-800-377-0928 to find out how.*



*photo courtesy of PJ Jordan,  
NSVN Volunteer*

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## HEAD AND NECK CANCER NEWS

*Novel biomarker appears predictive of outcome in patients with HPV-related head and neck cancers*

MD Anderson Cancer Center, HOUSTON - By analyzing variations in the level of human papillomavirus (HPV) in head and neck cancers, researchers at The University of Texas MD Anderson Cancer Center have discovered a gene signature associated with treatment response and survival in patients. Rather than simply classifying tumors as HPV-positive or HPV-negative, this biomarker may one day enable clinicians to better predict patient outcomes, ultimately allowing for reduced treatment intensity to minimize severe side effects.

The study, published today in *JCI Insight*, identified a subset of patients with HPV-positive head and neck, or oropharyngeal, cancers with a molecular profile and survival rates similar to HPV-negative cancers, which typically have poor outcomes. The researchers discovered a gene panel that distinguished this subgroup and appeared predictive of outcome in multiple independent cohorts.

According to the Centers for Disease Control and Prevention (CDC), more than 18,000 cases of oropharyngeal cancer are diagnosed each year in the U.S., with HPV infection responsible for roughly 70 percent of all cases.

Standard care for HPV-positive oropharyngeal cancers is a combination of chemotherapy and radiation with a five-year survival rate of approximately 85 percent, compared to just 55 percent for HPV-negative cancers, explained Curtis Pickering, Ph.D., assistant professor of Head and Neck Surgery and corresponding author on the study.

“Patients with HPV-positive oropharyngeal tumors are living a long time after radiation treatment, but often are left with significant long-term morbidity, including problems with speech or swallowing,” said Pickering. “Therefore, there’s a desire among clinicians to reduce, or de-escalate, therapy to lessen severe side effects. However, we currently don’t have good biomarkers to safely determine which patients are candidates for de-escalation.”

To better understand the role of HPV biology in patient outcome and identify biomarkers associated with treatment response, the research team analyzed data

from 80 oropharyngeal cancers included in The Cancer Genome Atlas (TCGA). Rather than simply classifying tumors as HPV-positive or HPV-negative, the researchers examined all tumors based on their level of HPV gene expression.

“That led us to an expression signature that neatly identified two different groups within the HPV-positive patients,” said Pickering. “The HPV-negative tumors were clearly different, but within HPV-positive there were two different groups. That was biologically interesting, but one HPV-positive subgroup had survival similar to those of HPV-negative patients.”

The researchers found an initial panel of 582 genes that distinguished these three subgroups -- a high HPV group, a low HPV group and an HPV-negative group -- each with statistically significant survival differences. Further analyses led to a panel of just 38 genes that are able to distinguish between the two HPV-positive subgroups.

A variety of genetic analyses confirmed the distinction between these groups, and the researchers discovered two viral genes not generally thought to be important for tumor progression that were significantly different between the HPV-positive groups. Further, cell line studies showed these genes to be correlated with radiation sensitivity, in alignment with responses seen in patients.

Recognizing the potential value of this gene signature for predicting treatment response, the researchers evaluated the biomarker in two independent patient cohorts of HPV-related oropharyngeal and cervical cancers. In each case, the gene panel appeared to be prognostic of survival and performed better than available clinical factors, such as smoking status and tumor size. After further refining their gene panel, the researchers believe that the biomarker could be reduced to as small as a single gene with similar prognostic ability.

“What I’m hoping is we’ve found some new fundamental aspects of HPV biology related to the carcinogenic process, the progression of the tumor and response to therapy,” said Pickering. “If we’re able to validate this in future studies, it could be incredibly clinically useful across several HPV-related tumor types.”

The current retrospective study was limited by relatively small cohort sizes and reliance on RNA sequencing data; therefore the research team hopes to evaluate their biomarker in prospective trials after developing an assay sufficient for clinical use.

###

*The study was supported by the National Institutes of Health (UL1TR001442); the National Cancer Institute (P30CA016672); and the HPV-Related Cancers Moon Shot™, part of MD Anderson’s Moon Shots Program™, a collaborative effort to accelerate the development of scientific discoveries into clinical advances that save patients’ lives. The authors have declared that no conflict of interest exists.*

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