

NEWS FROM S·P·O·H·N·C



VOL. 30 NO. 5

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

MARCH 2021



S·P·O·H·N·C
A PROGRAM OF SUPPORT
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PEOPLE WITH
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The Challenges of Telemedicine for Head and Neck Oncologic Patients During COVID-19

Karthik Rajasekaran, MD
& Vasiliki Triantafillou, MD

The COVID-19 pandemic is an unprecedented and historic event that presents unique challenges to patient care to medical providers worldwide. The pandemic and the ensuing rapid changes to medical practice have particularly affected head and neck cancer surgeons and their patients.



In an effort to balance the needs of our patients with the risks to patient and staff safety, we have been tasked with finding alternatives to the traditional office visit. In this commentary, we discuss how telemedicine can be incorporated into the head and neck surgery practice, the challenges that we have faced, and the dilemmas with which we have dealt in our efforts to fulfill the ongoing need for care of this unique patient population.

The COVID-19 pandemic has changed the practice of medicine and otolaryngology around the world, as priorities across health systems shift to accommodate a surge in patients with COVID-19. Otolaryngologists in particular are at elevated risk for occupational exposure and transmission of COVID-19. This is due to the high viral load in the nasopharynx and the aerosol-generating nature of many of the interventions that we perform, resulting in high rates of infection among members of our specialty. As the risk inherent to our work becomes apparent, multiple societies, including the

American Academy of Otolaryngology–Head and Neck Surgery and the American Head and Neck Society, have advised limiting patient care to “time-sensitive and emergent problems,” with a recommendation to consider telephone or video-based patient visits. This has ushered in an inexorable but necessary foray into telemedicine to connect with our patients, as in-person office visits have significantly reduced and, in some places, even come to a grinding halt.

For the head and neck specialist, this raises the question of how best to care for the patient with head and neck cancer. Our head and neck surgery practice serves patients at all stages of the cancer care spectrum. This includes new patients awaiting an appointment, patients seeking second opinions, patients in the midst of treatment, and patients undergoing continued oncologic surveillance.

Telemedicine is a disruptive process, especially when it must be adopted quickly out of necessity. There is little education in our field on how to best do a telemedicine visit. There are links to online materials and bulletins from our professional organizations outlining available products and medicolegal issues. There is telemedicine research, which in our field has been largely limited to remote areas and specific subspecialties and less commonly focused on the otolaryngology patient visit in general. In the case of head and neck, there is a handful of articles on provider-to-provider e-consultation or telemedicine to expedite the workup and oncologic intervention for a patient. Like many things at the moment, there is no guide on to how to best conduct oncologic surveillance over the phone or video. We are in uncharted waters.

Oncologic surveillance visits involve discussing new concerns and symptoms, reviewing imaging, and performing a physical examination and often a flexible laryngoscopy examination. Following this, the patient is provided either reassurance that the cancer has not recurred or guidance for next steps in management. While many otorhinolaryngology diagnoses are amenable to review of patient history and objective data remotely, the traditional head and neck physical and endoscopic examination remains our workhorse. Multiple head and neck cancer subsites are challenging, if not impossible, to see in the office, let alone in a telemedicine visit, without the technology that we have become accustomed to using. At the moment, it is also difficult to obtain imaging, as radiology offices are not scheduling elective scans. With any intervention, treatment, or imaging examination, we must weigh the risk of delay with that of possible exposure and iatrogenic contraction of COVID-19, especially in light of the growing evidence suggesting that patients with cancer may have greater risk of severe disease and higher mortality rates.

There are no right answers, only difficult case-by-case decisions for which we have no precedent. Our practice has been to opt for video telemedicine visits through our institution-

TELEMEDICINE continued on page 2

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chosen platform whenever possible. Only patients with new acute complaints or concerning issues are seen in the office. For patients who do not have any video capability, as is true for many patients in our population with head and neck cancer, we conduct a limited visit via phone call. Without our usual examination and surveillance options readily available, we have relied primarily on symptomatology and the subtleties of symptom change to guide our decisions. Despite these shortcomings, telemedicine at a minimum allows for at least some examination of a patient's overall health or complaint that may assist the physician in triage. We have been challenged to develop methods to virtually educate patients and their families on symptom and physical examination changes that should prompt a discussion with their doctors. Over the last month, these telemedicine visits have continuously evolved as we and our patients together navigate this new space of digital health services and the challenges that accompany them.



There is no arguing that a telemedicine video-based visit is preferable to a phone call and most definitely to the alternative of "no visit" for the care of our patients with head and neck cancer. Despite these challenges, we have heard how thankful our patients are to connect with their doctors during this time. We have also heard many patients echo the same concerns that we have. Patients undergoing oncologic care are a unique subset of patients who often form very close, longitudinal relationships with their providers. They are reliant on us, every time, to tell them that they are disease free or to guide them through options for the next steps. Our virtual declaration of "no evidence of disease" is not as reassuring as when we examine, touch, and interact with our patients in the usual way. This emotional burden is borne not just by our patients but by us as their physicians, too. Thus far, we have found that telemedicine both meets and yet falls short of our patients' needs and our goals as providers. Is this all that we can do for our patients?

Editors Note: Dr. Karthik Rajasekaran is a head & neck oncologic and reconstructive surgeon. He specializes in treating benign and malignant tumors of the nose, sinuses, oral cavity, oropharynx, larynx, thyroid, skin and salivary glands. Dr. Raj's research interests include outcomes for patients treated with advanced head and neck cancer, decreasing opioid use in head and neck cancer patients, and investigating methods to optimize perioperative care. He attended medical school at Rosalind Franklin University, completed his residency at the Cleveland Clinic Foundation and his Fellowship at Hospital of the University of Pennsylvania, where he is now the Director of Facial Trauma and Director of Quality Improvement Education & Assistant Professor of Otorhinolaryngology: Head and Neck Surgery.

Vasiliki Triantafyllou, MD is a 2019 graduate of the Perelman School of Medicine, University of Pennsylvania in Philadelphia, where she was awarded the Mary Ellis Bell prize for her research concerning Broncho-Vaxom® (OM-85 BV) soluble components stimulate sinonasal innate immunity. She has also co-authored several articles concerning otolaryngology/head and neck cancer.

HEAD AND NECK CANCER NEWS

The NCCN Releases Updated Protocol for Management of COVID-19 in Patients with Cancer

March 12, 2021- The National Comprehensive Cancer Network (NCCN) recently released the best practices for the management of COVID-19 infection in patients with cancer.

This week, the National Comprehensive Cancer Network (NCCN) released an updated set of guidelines for how to best manage and treat COVID-19 in patients with cancer. Using data from more than 150 studies covering various topics, these recommendations cover a range of topics including who should be tested, when to modify treatment, and more.

As noted in the guidelines, individuals with cancer are at an increased risk (29.4%) for severe disease and mortality from COVID-19 compared to those without (10.2%). Notably, these percentages vary depending on cancer type, treatment type, and stages of therapy. But given that the information about how the virus impacts patients with cancer is mostly based on observational data and has been gathered from larger population studies not focused solely on those with cancer, the NCCN gathered the latest data from a number of sources including the American Society of Hematology, the American Society of Clinical Oncology, the Society of Surgical Oncology and more.

“Our mission to help people with cancer live better lives is more important than ever right now,” said Dr. Wui-Jin Koh, chief medical officer of the NCCN, in a news release. “This new guidance, along with other expanding resources at [NCCN.org/covid-19](https://www.nccn.org/covid-19), will help to answer many of the treatment questions that have come up over the course of the pandemic.”

The guidelines provide information and recommendations on several topics, including:

Testing – In addition to what tests are available, the guidelines also cover what tests should be used and when depending on what point a patient is at in their cancer treatment. Of note, the authors found that the test for antibodies against SARS-CoV-2 or nucleocapsid antigens is not recommended as the only test when it comes to clinical decisions in those with cancer, due to the fact that these patients may not develop

robust antibody responses after infection or vaccination.

Isolation – Given the differing opinions on the appropriate isolation period lengths for individuals at different points of the cancer spectrum, the guidelines now recommend that patients who are severely immunocompromised should isolate for up to 20 days after symptom onset. If the patient was asymptomatic, isolation can end 10 days after the date of their first positive test for SARS-CoV-2 RNA.

Treatment Delays – The immune-system-compromising effects of cytotoxic chemotherapy create several questions for patients that contract COVID-19, all of which the guidelines aim to answer. Ideally, mild or moderately symptomatic patients with non-hematologic cancer should delay chemotherapy until the resolution of all symptoms, as well as a minimum of 10 days after symptoms started.

Severely symptomatic and/or patients with hematologic malignancies should have chemotherapy delayed until symptoms stop, with a minimum of 20 days after they began. Asymptomatic patients should delay

chemotherapy for a minimum of 10 days after the date of their first positive test and should then be monitored for 14 days.

Additionally, guidance is offered for patients receiving hematopoietic cell transplantation (HCT) or CAR-T cell therapy.

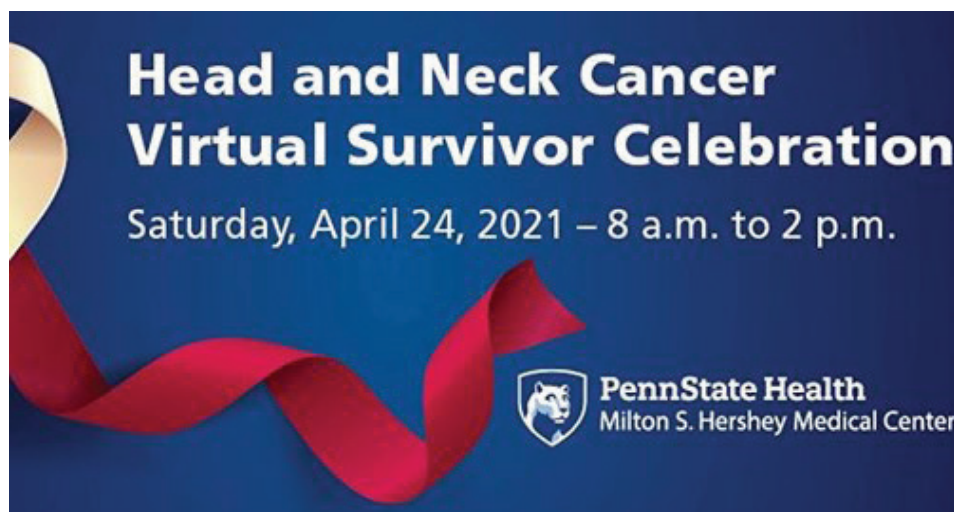
The NCCN does note that if chemotherapy or another treatment is urgent due to an uncontrolled cancer, then it should be administered at the judgement of the physician.

*“Speaking for so many,
I am confident and aware that
these newsletters
mean the world to us.
Patients, survivors, and
especially caregivers truly
need and appreciate this
great information.”*

~ Gene M.

Chapter News

**SPOHNC's Penn Hershey Chapter Support Group
Hosts a Virtual Celebration**



*In recognition of April Awareness, SPOHNC's Penn Hershey Chapter Support Group is hosting a **Virtual Survivorship Celebration**. For more information or to register for this event, check out SPOHNC's Facebook page, or go to <https://www.eventbrite.com/o/departments-of-otolaryngology-penn-state-milton-s-hershey-medical-center-31156383635>*

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HEAD AND NECK CANCER NEWS

To improve immunotherapy, researchers look to shift immune cells' access to sugar

February 16, 2021- Memorial Sloan Kettering Cancer Center - New research suggests that a way to improve immunotherapy is by altering immune cells' access to sugar.

Sugar is an important nutrient. All cells use sugar as a vital source of energy and building blocks. For immune cells, gobbling up sugar is a good thing, since it means getting enough nutrients to grow and divide for stronger immune responses. But cancer cells use sugar for more nefarious ends.

So, what happens when tumor cells and immune cells battle for access to the same supply of sugar? That's the central question that Memorial Sloan Kettering researchers Taha Merghoub, Jedd Wolchok, and Roberta Zappasodi explore in a new study published February 15 in the journal *Nature*.

Using mouse models and data from human patients, the researchers found a direct relationship between the amount of sugar -- specifically glucose -- that a tumor consumes and the effectiveness of immunotherapy: The more sugar the tumor consumed, the less effective the immunotherapy.

The findings suggest that blocking cancer cells' use of sugar could tip the scales in favor of immune cells, especially when they are activated by immunotherapy drugs.

"If we reduce a tumor's use of glucose, then we free up more of it for immune cells to use, which benefits the immune response," says Dr. Merghoub, who co-led the research effort.

"What we think we've identified is a new means to improve checkpoint blockade immunotherapy," adds Dr. Wolchok. Immune checkpoint inhibitors release the brakes on immune cells and can provide lasting benefits for people with cancer, but they do not work for everyone. The new research may provide a way to boost their effectiveness.

Dr. Wolchok, Chief of the Immunology Service in the Human Oncology and Pathogenesis Program at MSK, also directs the Parker Institute for Cancer Immunotherapy at MSK and co-directs the Ludwig Center for Cancer Immunotherapy at MSK.

Vying for Resources

To examine the relationship between tumor cells' use of glucose and response

to immunotherapy, the researchers turned to a mouse model of breast cancer that is highly glycolytic -- meaning it uses a lot of sugar to grow. In the first set of tumors, the researchers genetically knocked down a key enzyme cells require to rapidly consume glucose in a process called glycolysis. In the second set, the enzyme was left alone. Each set of tumors was grown in mice and then the mice were treated with checkpoint inhibitors targeting CTLA-4 before having surgery to remove the tumor. The results: The mice whose tumors consumed less sugar survived longer and had a far lower rate of metastasis (when the cancer spreads) than the mice with tumors that used more glucose. This indicated an improved response to immunotherapy in mice whose tumors consumed less glucose.

Moreover, the improved immune response exhibited memory. When

researchers re-implanted tumors in the mice exposed to the less-glycolytic tumors, tumor growth remained suppressed. By contrast, mice exposed to the more-glycolytic tumors were not able to control the growth of re-implanted tumors. The team also looked at human data. When they measured glucose use by tumors and compared that to the number of immune cells present in a tumor, they found that the two measures were inversely correlated: The higher the glucose use by tumors, the fewer immune cells present.

Releasing Multiple Brakes

When it comes to immune checkpoint blockade, two types of T cells are crucially important -- effector T cells and regulatory T cells (Tregs). Effector T cells are the ones that actually attack cancer cells and kill them, whereas Tregs serve as a kind of brake on the effector T cells.

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FREE WEBINAR

EXPLORING CLINICAL TRIALS IN HEAD AND NECK CANCER

Thursday, April 15th, 2021
1:00 PM – 2:00 PM ET

For a discussion on clinical trials within head and neck cancers as seen through the eyes of an oncologist, researcher and patient.



Survivor Presenter:
Thomas Bennett
Head and Neck Cancer Survivor



Medical Presenter:
Sarah Roberts, MS,
ACSM CET
Community Outreach and Engagement
Coordinator University of Colorado
Cancer Center



Medical Presenter:
Dan Zandberg, M.D.
Director of the Head and Neck and
Thyroid cancer disease sections for
the division of
Hematology/Oncology and the
Medical Oncology Co-Leader of
the University of Pittsburgh
Medical Center Hillman Head and
Neck Cancer Program



Medical Presenter:
Oliver Rosen, M.D.
Chief Medical Officer,
SQZ Biotechnologies





Presented by:

www.headandneck.org/survivorship-webinars/

*Join us as we listen to SPOHNC's newest
Medical Advisory Board member, Dan Zandberg, MD*

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It turns out that glucose affects these two T cell types differently. More available glucose boosts the effector T cells' killing ability. With Tregs, more glucose means they lose their ability to apply the brakes. That means that freeing up glucose for use by immune cells is doubly beneficial at giving a boost to immunotherapy drugs.

"It was surprising and exciting to see that CTLA-4 blockade induces Tregs to use glucose and that this in turn reduces the suppression activity of these cells," says Dr. Zappasodi, a former Parker Institute Bridge Scholar in the Merghoub-Wolchok lab and now a faculty member at Weill Cornell Medicine.

"The implication is that for tumors that are highly glycolytic and don't respond to immune checkpoint blockade, one way of overcoming this resistance is to target tumor glycolysis with drugs," Dr. Merghoub adds.

The feasibility of using sugar to boost immune responses depends on being able to preferentially limit glucose use by tumors -- and that's where it gets tricky. Existing drugs that block sugar use by cancer cells will also block sugar use by immune cells, which would defeat the purpose. What is needed are drugs that can prevent tumor cells from using glucose while allowing immune cells to use it freely. The team has a few leads and is exploring them now.

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Chapter News

SPOHNC Palm Coast Northeast Hosts 8th Annual Move to Music Event

The challenges presented by the year 2020 were unimaginable. Who would have thought, last year at this time, that we would all be at home, isolated for the entire year, waiting for life to get back to "normal." It seems, actually, that a common expression used by head and neck cancer survivors following treatment - "the new normal" would now be a commonplace term for the way things are - at least for now.

So many important occasions - family gatherings, sporting events, concerts and fundraising events - all were to be put on hold, indefinitely. One such event that so many look forward to each year, was the annual Move to Music exercise class/fundraising event, held each year in Palm Coast, Florida, hosted by SPOHNC Chapter Facilitators, Amy and Lewis Beilman. Amy and Lewis and their dedicated group of volunteers have hosted this amazing event each year for the past 8, and this year, despite delays, challenges, setbacks and COVID 19, the Beilman's, and the Grand Haven community rose to the occasion, and they did it again!!!

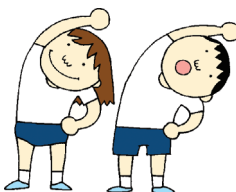
The 8th Annual Move to Music celebration took place on Wednesday and Friday, October 14th and 16th. There were 2 separate exercise classes...held at the Wild Oaks Basketball Court. Typically, the event is held indoors but due to social distancing and additional restrictions, this was not possible. Driven, enthusiastic and never known to give up, the Beilman's found a way around the limitations, and created a new event. Each class was limited to 25 participants, and Lewis' music mix was inspiring, as usual.

Then, on Saturday morning, October 17th from 9-11am at the Creekside Pool

Area at Grand Haven, there was the usual amazing display of silent auction items and a huge number of raffle items on display and open for bids and raffle ticket sales. T shirts and hats were also on sale. Silent Auction and raffle ticket sales closed in the late morning, and the raffle pull followed. In order to encourage social distancing and safety, winners did not need to be present, and could have their winnings delivered to their doorstep. All proceeds of Move to Music benefitted SPOHNC.

Each year, for the last 8, Amy and Lewis have poured their heart and soul into Move to Music, and each year, it just gets better and better. They outdid themselves again in 2020 - pandemic and all!!!!

SPOHNC is eternally grateful to this amazing couple, for their tireless dedication to SPOHNC, and especially to the patients and survivors they encourage, step by step, along the cancer journey and beyond. We are so humbled by your generosity of heart and spirit, and we are blessed to count you among our SPOHNC family, not just as supporters of our organization, but as the dear friends you have become to us all. We love you, Amy and Lewis, and we thank you, for never giving up, and for marching on, as you always say!!



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Chapter News

Boston, MA SPOHNC Chapter Celebrates 20 Years

SPOHNC's Boston, Massachusetts Chapter support group just celebrated a milestone, and even in this time of crisis – they made it work. We believe it was SPOHNC's first ever Anniversary Celebration via Zoom. Congratulations!!

While so much has changed for many during this last year, what has not changed is the unwavering dedication and commitment of our SPOHNC Chapter Facilitators and Co-Facilitators, one and all. You have all continued with your mission of supporting head and neck cancer patients and survivors, as they navigate the uncertainty of COVID 19 and how it has affected their treatment, survivorship and their lives. Somehow, you have all met the year of challenges head on, and SPOHNC is forever grateful.

One such Facilitator is survivor and healthcare professional, Valerie Goldstein. Valerie started the Boston, Massachusetts SPOHNC Chapter 20 years ago, and has kept it going, enthusiastically, for the last 20 years. Not one to settle, even in the face of a pandemic, Valerie connected with SPOHNC indicating her desire to host a virtual celebration of their 20 years of supporting each other, and she invited SPOHNC to attend. SPOHNC, in turn, invited SPOHNC Board member, and world renowned and highly esteemed head and

neck cancer surgeon, Eugene N. Myers, MD, FACS, FRCS, Edin (Hon), to join the celebration and congratulate Valerie and her group on 20 years, and give a brief overview of the diagnosis and treatment of cancers of the head and neck. Dr. Myers gladly accepted the invitation and was honored to present to the group. The group was thrilled that Dr. Myers was able to participate, and all listened intently, asked questions and expressed their gratitude to Dr. Myers for joining their celebration.

SPOHNC also participated in the virtual celebration and presented Valerie with a framed certificate and a gift, to be mailed to her, post meeting. As part of her presentation to the support group, SPOHNC's Executive Director, Mary Ann Caputo, commended Valerie, expressing these heartfelt sentiments on behalf of the organization... "SPOHNC is forever grateful to you for your commitment and dedication for all your years of service. You are a blessing to so many and we could not reach each and every patient without volunteers like yourself who give so much!!"

Valerie expressed her gratitude to Dr. Myers on behalf of the support group, saying "My sincerest thanks for your wonderful presentation to our SPOHNC BOSTON support group. I learned a lot of new things

I didn't know about treatment and diagnosis, even after many years of running the group, and I know that our group members gained a lot of good knowledge as well. It really means a lot when someone with

your level of expertise takes the time to help our group members! Many thanks again for helping SPOHNC BOSTON make our 20th Anniversary Celebration special — and for all you do for SPOHNC!"

The event concluded with well wishes for continuing support from SPOHNC and Dr. Myers, and everyone left

feeling blessed and grateful for the day. It was a wonderful "meeting" and all who attended were very pleased to be part of the momentous occasion.



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



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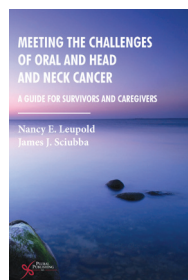
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**Magnificent March Recipes from
“Eat Well Stay Nourished A Recipe and Resource Guide
For Coping With Eating Challenges”**

Compiled and Edited by Nancy E. Leupold, Founder, in memoriam

Quiche with Crumbled Bacon (from Volume Two)

1 ready-made 9” pie shell
8 slices cooked bacon, crumbled
4 eggs
1 ½ c. whole milk
½ tsp. salt
Dash of pepper
8 oz. shredded swiss cheese
2 Tbsp. flour



Heat oven to 350 degrees. Mix eggs, milk and seasonings. Toss cheese with flour. Add cheese and crumbled bacon to egg mixture. Pour into pie shell. Bake 40 to 45 minutes or until golden brown on top. Test by entering a knife in the center of the pie. If it comes out clean, the pie is done. Let stand 10 minutes before slicing. Serves 8. 419 calories/serving.

~ Mary Ryan, IN



Fluffy Blueberry Fruit Dessert (from Volume Two)

¼ cup whipped topping
¼ cup pureed blueberry pie filling

Fold whipped topping into pie filling until mixed. Refrigerate until served.

Yields 1 serving - 132 calories/serving



~ Staff of UPMC, PA



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Time for Sharing... *The head and neck cancer journey* *– a personal experience fighting tongue cancer*

I have always been a fit lady, hiking ten miles on a Sunday, dancing jive twice a week, Pilates, pump class, yoga and aerobics. In 2011, I was advised by my dentist to get the white spot on my tongue checked. The biopsy showed no sign of cancer.

In 2018, the white patch was still there,



I wasn't feeling great and started having recurrent shingles. I visited my GP to be told it was just my tooth rubbing on my tongue. During three further visits I was met with the same reply but I knew my body,

my body was fighting something. I insisted on getting a referral to an ear nose and throat consultant. I was forever coughing to clear my throat. I was told the patch was oral lichen planus and probably due to my tooth rubbing on my tongue. I was advised to get that side of my teeth filed down which I did. January 2019, I was starting to get pain in my mouth. Mouth cancer tastes foul. It hurt to cough, to spit, to yawn and to eat. I was then offered a biopsy just before a trip to Sri Lanka. I asked if they would text the result.

I didn't receive any news but a friend called saying the consultant wanted me to have a CT scan on my return. I knew I had cancer as a CT scan was to check for secondaries. After the holiday, I returned to the UK and went for the scan which confirmed the sad news that I had been diagnosed with stage 2 squamous cell carcinoma but it was aggressive. It was 1.5cm with an area of dysplasia around the tumour.

Eating was getting difficult. I was scared as I think most cancer patients go through the feeling "Am I going to die." Followed by "Why me?" I met with a charming consultant who explained the options and asked me what was important to me. I was frightened I wouldn't be able to talk. My voice was important to me as a lecturer and TV presenter. I chose option 3 which avoided radiotherapy but involved an eleven-hour operation. I would need a neck

dissection to check for cancer in the lymph glands and a graft to be harvested from my forearm to reconstruct my tongue together with a graft from my abdomen to fill the hole in my arm. As I still wear a bikini, I asked the surgeon to make sure the abdomen graft was within the bikini bottom edges. We discussed radiotherapy but I didn't want it so kept thinking positive thoughts that there would be no cancer in the lymph nodes.

Having worked in television I suggested to a friend at the BBC that they follow me as perhaps what I had learned might help other head and neck cancer patients. I decided to try practicing speaking with my tongue in the bottom of my mouth simulating talking without a tongue. I used trips to the bathroom as a trigger and would work through the alphabet but naming letters and phonetically.

I have always looked after myself, eating a sane diet and exercising. I didn't eat fast food, was a non-smoker and only cooked fresh food with lots of fruit and vegetables. I enjoyed a glass of wine but in moderation.

During the month before the operation, the tumour which I nicknamed Spartacus grew and the taste was revolting. The pain was intense. The BBC filmed me a few days before the operation and then during the procedure. I got organised at home before the operation with:

- Lipsyl - lip softener
- Baby toothbrush and soft electric toothbrush and mouthwash
- Clothes that open at the front
- Pestle and mortar for tablets
- 0.5, 1 and 2kg weights, 2 pulleys and 1/4" yachting cord
- Resistance bands
- NutriBullet or similar fine liquidiser
- Shower sleeve
- Aloe Vera pure gel pharmaceutical grade (not aloe vera drink)
- Bio oil and curry leaf oil
- Real honey, peanut butter, semolina, porridge

I also arranged the following:

- Put in a system if speech very difficult for answering the phone
- Schedule friends to come talk and walk with you post op

- Arrange the kitchen to facilitate one-handed operation
- Manage shopping as can't drive for six weeks

At the pre-op I was asked to put on a chart where my fitness level was and the top level was 'can walk upstairs without getting breathless.' I laughed and told the nurse that despite being 68 I was very fit and did lots of regular exercise. He replied "hey put 10 out of 10." I found out that my heart was not in good shape. I had Atrial Fibrillation and the atria were enlarged but they would monitor me well during surgery.

The operation was scheduled for my birthday on May 1, 2019. I had friends say how awful but for me it was going to be a great birthday present to get rid of the cancer. I decided to ask the theatre team to sing me happy birthday as I was going under rather than the usual countdown. I remember two rounds as they seem to be putting in cannulas all over my legs and arms. Apparently, my blood pressure and pulse remained normal throughout the operation and my surgeon put that down to my fitness level. I was woken twenty-eight hours later.

When my friend walked into intensive care to say hello, I replied "Hi." Wow I had a voice despite the huge swollen lump in my mouth. The following days were difficult but the worst issue was the lack of sleep. Getting my blood pressure and pulse taken every two hours and also a Doppler machine being placed on my flap to ensure the blood was flowing was never going to allow me a good night's sleep.

It was busy in the ward, changing my feeding tubes, giving me medication, speech and physiotherapy exercises. Initially, I needed help to use the bathroom and I longed for a shower. I followed the exercises religiously but was unable to do many as the pain was intense, particularly lifting my arm on the side of the neck dissection. Then the speech therapist and the dietician said that I would have to show I could swallow or I would be fitted with a PEG. (Percutaneous endoscopic gastrostomy tube goes into your stomach through an opening made on the outside of the abdomen.) I didn't want this so with the feeding tubes still in place,

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I sat up one night and any bit of saliva I could muster up, I practiced swallowing. The day they asked me to swallow by putting my neck forward, I could do it. The tubes were then removed, uncomfortable but not painful. I was given puree but that evening a friend brought me in a Tiramisu and it was a chocolate explosion in my mouth. Having lost 30% of my taste buds, tastes were going to be slightly different. I tried some thicker purees but lumps were a bit difficult as my swollen tongue could not go and find them so food would appear in my mouth hours after taking it. The pain came when they decided to remove my drips. A delightful Scottish nurse told me to wriggle my toes while she pulled what seemed to be two very long tubes from my neck.

I should have been in hospital two weeks but after eleven days my surgeon agreed to discharge me in order to get some sleep.

I stayed with a friend for a week, practicing the speech therapy and physiotherapy exercises. Doing the latter to music allowed me to exercise for longer and it didn't seem a chore. Two weeks later the moment of truth, as I was to go to the Churchill Hospital to find out if the lymph nodes in my neck were cancerous. I imagined they were not every day. To my utter delight, the surgeon confirmed this and I wanted to hug him. I was offered radiotherapy as a precaution but I researched the statistics and decided against it.

I went to my house and the first night alone felt quite scary. The next day I sat in my conservatory where the ashes from my mum are in a huge pot of birds of paradise. I am not religious but heard a voice. "You are going to live another 24 years." Having a shower was still difficult with a plastic arm band and washing or drying my hair one-handed not as effective as with two. As the days passed, I got stronger and after a month a friend took me to the Dorset coast. I felt really alive and even climbed a hill where at the top I could raise my grafted arm without pain and without medication. Hotel food was a little tricky as puree seems to have a different connotation for different people.

Somewhat depressed at my slow physical recovery in the June I went to France. Luc, a physiotherapist I had seen a few years back after a dance accident took one look at me and said "OK well I know you. Enough of eight repetitions three times a day, 100 repetitions twice a day." Within a week, my trapezius above

my collar bone popped up and another month later my biceps were in action. I have kept exercising ever since.

On reflection, no one had told me about the mental side of dealing with cancer. As a stable person having frequent emotional crashes was tough but they grew less and less. I had been told to expect a new normal but with no information as to what that new normal would be. It is difficult for the surgeons as each surgical intervention is unique, the fitness level before surgery is different for everyone and the position and size of the tumour also has an impact on recovery.



Milestones

- 2 days walked around the ICU
- 4 days physiotherapist basic movements
- 5 days speech therapist
- 10 days learnt to swallow all food pureed
- 11 days discharged.....SLEEP
- 16 days lymph nodes clear of cancer
- 17 days Exercising as per Churchill guide can't raise arms without codeine
- 18 days arm swollen, can't move fingers
- 23 days managed a 2-mile walk
- 35 days stitches not dissolving in arm so removed many myself to relieve stretching
- 42 days started weekly physiotherapy
- Sleeping getting easier
- 42 days went to Heads2gether
- 49 days "Had an emotional crash. Fed up with arm pain and also eating mushy food. Often omitted when puree got cold. Not recovering as quickly as I thought and it has hit me that the new normal is far from my normal.
- 50 days can raise left arm 60 degrees
- 51 days managed a soft-boiled egg using a grapefruit spoon
- 63 days started physio in France

- 100 repetitions set up pulley at home
- 67 days muscle above collar bone firing
- 70 days trying different foods
- 71 days swam 12 lengths
- 72 days losing weight (-11lbs)
- 73 days could raise arm almost above head but painful
- 78 days driving with difficulty
- 79 days pubic hair growing on graft and some hair on tongue flap
- 120 days biceps firing
- 165 days ate a lightly seared tuna steak
- 170 days went jiving but got very tired and muscles aching
- 180 days celebrated being cancer free indoor skydiving
- 190 days weekly routine includes Pilates, fitness Pilates, aerobics, Kundalini yoga and hiking 10 miles
- 200 days wrists getting stronger still exercising went rock climbing

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**"Together Facing
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To register, go to:
<https://www.foxchase.org/events/together-facing-head-and-neck-cancer-2021>

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- 200+ days trying 4 small meals a day and getting creative
- 365 days eating a pescatarian diet given up on meat
- 400 days Hearing loss 100% on the side of my neck dissection requiring physical and medicinal therapy.
- 500 days back to pre-surgery weight still exercising and hearing back to 93% without needing hearing aids.

Having had a partial glossectomy there are ongoing problems.

- Managing the flap
- Cleaning teeth
- The flap - taste and biting
- Unable to chew just "squidge" food with tongue and right-side teeth
- Finding food in mouth hours after eating
- Twisting my head
- Unable to spit (phlegm, toothpaste etc.)
- Muscles and joints need regular exercise or stiffen up.
- Eating in or out – Most restaurants are accommodating but not all

So to offer any advice to other patients, I would say patience, it is a slow process. Stay positive and stay away from negative people and negative thoughts. Exercise everything from your tongue to your arms, your jaw... everything. Find a support group and help others.

~ headandneckcancerfitness@gmail.com

Janet West MSc FRSA resides in the UK. She has been a pilot, a lecturer and a TV presenter. She has developed her own YouTube channel Head and Neck Cancer Fitness where exercises after head and neck cancer can be followed. <https://www.youtube.com/channel/UC7H2d-UFYGqZv8YdbEBvdYg>



HEAD AND NECK CANCER NEWS

Deactivating cancer cell gene boosts immunotherapy for head & neck cancers

23-MAR-2021 - *UCLA discovery opens a pathway toward the discovery more effective treatments*

By targeting an enzyme that plays a key role in head and neck cancer cells, researchers from the UCLA School of Dentistry were able to significantly slow the growth and spread of tumors in mice and enhance the effectiveness of an immunotherapy to which these types of cancers often become resistant.

Their findings, published online in the journal *Molecular Cell*, could help researchers develop more refined approaches to combatting highly invasive head and neck squamous cell cancers, which primarily affect the mouth, nose and throat.

Immunotherapy, which is used as a clinical treatment for various cancers, harnesses the body's natural defenses to combat disease. Yet some cancers, including head and neck squamous cell carcinomas, don't respond as well to the therapy as others do. The prognosis for these head and neck cancers is poor, with a high five-year mortality rate, and there is an urgent need for effective treatments.

The UCLA research team, led by distinguished professor Dr. Cun-Yu Wang, chair of oral biology at the dentistry school, demonstrated that by targeting a vulnerability in the cellular process of tumor duplication and immunity, they could affect tumor cells' response to immunotherapy.

The enzyme they focused on, KDM4A, is what is known as an epigenetic factor -- a molecule that regulates gene expression, silencing some genes in cells and activating others. In squamous cell head and neck cancers, overexpression of KDM4A promotes gene expression associated with cancer cell replication and spread.

It is well known that tumor cells can spread undetected by the immune system and, without surveillance, can metastasize to lymph nodes or other parts of the body. In this instance, tumor cells that develop in the epithelial layer that lines the structures of the head and neck can turn into head and neck squamous cell carcinoma when unchecked.

Cancer cell replication occurs through the abnormal spread and activation of signaling pathways for cancer cells, and

the researchers asked the question: If we can disrupt these processes and identify a vulnerability, can we change the body's response to fighting cancer cells and its response to outside immunotherapy?

"We know that the KDM4A gene plays a critical role in cancer cell replication and spread, so we focused our study on removing this gene to see if we would get an opposite response," said Wang, the study's corresponding author and a member of the UCLA Jonsson Comprehensive Cancer Center. By removing the KDM4A gene in their mouse models, the researchers witnessed a notable decrease in squamous cell carcinomas and far less metastasis of cancer to the lymph nodes -- a precursor to the spread of the disease throughout the body. Surprisingly, they also discovered that the KDM4A's removal also led to the recruitment and activation of the body's infection-fighting T cells, which killed cancer cells and stimulated inherent tumor immunity.

They then sought to uncover why the squamous carcinoma cells had such a poor response to immunotherapy treatment. In another set of mouse models, they again removed KDM4A and introduced a PD-1 blockade, which signals immunotherapy drugs to attack cancer cells. The combination of immunotherapy and KDM4A removal further decreased squamous cell cancer growth and lymph node metastasis.

Next, the researchers tested whether a small-molecule inhibitor of KDM4A could improve the efficacy of the original PD-1 blockade-based immunotherapy. They found that the inhibitor also significantly helped remove cancer stem cells, which are associated with cancer relapse.

The findings hold promise for the development of more specific inhibitors for KDM4A and more effective cancer immunotherapies. "I am continuously impressed by Dr. Cun-Yu Wang and his team for breaking through barriers in our understanding of cancer-causing cellular processes," said Dr. Paul Krebsbach, dean and professor at the UCLA School of Dentistry. "The results of this study have major implications for the development of more effective, life-saving cancer therapies."

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