

# NEWS FROM S•P•O•H•N•C



VOL. 30 NO. 2

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

OCTOBER 2020



**S•P•O•H•N•C**  
A PROGRAM OF SUPPORT  
FOR  
PEOPLE WITH  
ORAL AND  
HEAD AND NECK CANCER

## Exploring Innovation in Cancer Therapy with Nanophysics

Laurent Levy, PhD

We find ourselves in an exciting time for innovation in the treatment of head and neck cancer. New treatments such as immunotherapy and increased precision in the delivery of radiation are examples of methods that are being evaluated in clinical trials, some of which have already shown the ability to improve therapeutic outcomes for patients.



While these advancements are encouraging, there is still room for improvement as the oncology community continually strives to maximize the efficacy of treatment while minimizing side effects that impact a patient's quality of life. As a physicist, by education and training, my focus has always been the intersection of physics and biology. Let us examine

how these areas of interest could lead to another new option for head and neck cancer patients.

### Discovering Nano

As I was preparing to apply to postdoctoral programs in the mid-90s, there was an emerging subdiscipline within the physics landscape called "nanophysics." The foundation of this area of study was the idea that the properties of physical materials could and would change if they were reduced to the "nanometric scale." A material can be described as "nanometric" or "nano" if it is between one and one hundred nanometers in size. To put that in perspective, if you were to take a human hair and cut it 3000 times at its diameter, you would have a nanomaterial.

From my perspective, the beauty of this field was two-fold. First, once we understood that the physical properties of a material changed when reduced in scale, we could isolate the properties we wanted to apply and design "nanoparticles" with specific functional utility. Second, many biological mechanisms are at the same scale, or even larger than a nanomaterial. For example, the average human cell is 10,000 nanometers in diameter. As a result, nanotechnology applications like nanoparticles could potentially cross natural barriers within cells that are unavailable to other types of therapies and interact with DNA or small proteins in the blood, organs, tissues, or cells. This idea became the foundation for the field of study called "nanomedicine."

The idea for my postdoctoral thesis was the question, "Can I impact the physics of a cell without touching it?" This question led me and my peers at the State University of New York in Buffalo to design a magnetic nanoparticle that could "spin" the nucleus of a cell. Even to this day, much of the nanomedicine field focuses on helping with the "delivery" of other agents within the body (i.e. the nanomaterial is used to help a drug get to where it needs to go) or for diagnostics (i.e. the nanomaterial is introduced to an area within the body so imaging tools like MRI can visualize them and researchers can better understand what is happening). The success of our magnetic nanoparticle experiment showed me that nanomaterials could take a more active role in treatment. We could use nanomaterials as an active agent, rather than purely as a vehicle for other treatments.

After the magnetic nanoparticle, we thought it would be interesting to try designing a nanoparticle that could absorb radiation. With this idea in mind, in 2003 we spun off the company Nanobiotix to bring the idea to life. We knew there was an opportunity for a company dedicated to using the principles of nanophysics to develop disruptive solutions to treat major diseases, and we wanted to lead that effort. Our radiation-absorbing nanoparticle evolved into what is now the lead product candidate for Nanobiotix: NBTXR3.

### Developing Nanomedicine

NBTXR3 is designed as a novel "radioenhancer." The technology is composed of functionalized hafnium oxide nanoparticles, administered one time via injection directly into solid tumors, and activated by radiation therapy. Hafnium oxide has high electron density and is therefore able to absorb a larger quantity of radiation than the molecules already present in the cells. After absorbing radiation, the nanoparticles cause a larger dose of energy to be deposited within the tumor cells. This mechanism of action increases the tumor-killing effect of the radiation therapy treatment. The hafnium oxide nanoparticles are biologically inert outside of the presence of radiation, so the damage only occurs in the area where the nanoparticles are present and while they are activated by

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Founder  
*In memoriam*

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radiation therapy<sup>1</sup>. It is also worth noting that because the mechanism of action of NBTXR3 is physical, rather than biological or chemical, in theory the effect should be scalable across tumor types.

Given that radiation therapy is part of the standard of care in approximately 50% of cancer diagnoses, our next step was to begin developing NBTXR3 in oncology<sup>2</sup>. The first indication we targeted was soft tissue sarcoma. Soft-tissue sarcomas (STS) are cancers that arise from different types of tissues such as fat cells, muscles, joint structures, and small vessels.

Patients with high-risk STS have a poor prognosis; they need surgery to remove their tumor, and their only therapeutic option before surgery is radiotherapy<sup>3</sup>. Treatment with NBTXR3 activated by radiation therapy aimed to destroy the tumor more efficiently, allowing for complete malignant tissue extraction during surgery.

As published in *The Lancet Oncology*, NBTXR3 showed statistically significant positive results in a phase II/III randomized trial<sup>4</sup>. Approximately twice as many patients with STS who received NBTXR3 activated by radiation therapy achieved a pathological complete response, which was the primary endpoint of the trial. The trial also achieved its secondary endpoint, with improvement in surgical resection margin rate for patients who received NBTXR3 activated by radiation therapy compared to patients treated with radiation therapy alone. Combined with a strong safety profile that was consistent with phase I results, these data support NBTXR3 activated by radiation therapy as an option to improve treatment outcomes for patients with STS.

Building on our proof of concept in STS, our next step was to target another solid tumor indication where radiation therapy was a major part of the standard of care. 70-80% of all patients with head and neck cancer will receive radiation therapy as part of their treatment<sup>5</sup>. While radiation remains a critical tool in combatting the disease, many patients still face limits which may prevent the therapy from improving their lives for significant periods of time. The limitations of radiation therapy are primarily driven by the inability to administer a dose that is strong enough to kill the targeted tumor without harming surrounding healthy tissue. This is compounded when the tumor is within or near sensitive organs. A large proportion of head and neck cancers are found in the oral cavity and the oropharynx, which contain structures that play a crucial role in swallowing, breathing, and speech. As a result, patients are faced with a disease that the current standard of care may not cure, and in the process of receiving treatment, they may lose function or experience trauma that will impact them for the rest of their lives. Elderly patients with head and neck cancer can be at an even greater disadvantage, as they are often ineligible for standard of care treatments like platinum-based chemotherapy due to associated toxicities<sup>6</sup>. These patients may also have other pre-existing medical conditions that further limit their treatment options. We knew that innovation might bring benefits to this group and were called to begin evaluating the potential.

As such, Nanobiotix launched Study 102 — a European phase I dose escalation/dose expansion trial evaluating the safety, feasibility and recommended dose of NBTXR3 in elderly patients (aged greater than 70 years) with locally advanced head and neck cancer, who are ineligible for cisplatin or intolerant to cetuximab. The only available treatment for these patients is radiation therapy

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as their condition does not allow them to receive the combination of radiation therapy and chemotherapy.

Patients recruited in the dose escalation part of the trial received doses of either 5%, 10%, 15%, or 22% of the baseline tumor volume. Results showed that there were no serious adverse events (SAEs) related to NBTXR3, and each dose showed a good safety profile. Disease control was observed at all doses and there were no dose-limiting toxicities (DLTs) observed with NBTXR3<sup>7</sup>.

Given that there were no DLTs or SAEs in the dose escalation part, and that there were early signs that NBTXR3 activated by radiation therapy could improve outcomes for some patients, an additional dose expansion cohort was launched to increase the sample size and further investigate the early signs of efficacy.

The dose expansion part of the trial is ongoing and continues to evaluate NBTXR3 activated by radiation therapy in patients with locally advanced head and neck cancer ineligible for platinum-based chemotherapy. The next step in the clinical trial process will be to launch a phase III registration trial evaluating whether the product provides a clinically meaningful improvement in treatment outcomes for patients.

### To Infinity and Beyond

To this day, the ambition of our team remains to use physics to expand what is possible for human beings. We will continue to develop NBTXR3 and, hopefully, prove that it can benefit patients with cancer wherever radiation therapy is a part of the treatment paradigm. We will also develop new nanotechnology applications to address other unmet needs in the treatment landscape. Most importantly, we will always champion the need for innovation to provide disruptive solutions and improve treatment outcomes for patients everywhere.

*NBTXR3 is an investigational product that is currently being evaluated in several clinical trials. NBTXR3 is not available for commercial use and has not been approved as safe and effective by the U.S. Food and Drug Administration.*

*Editors Note: Laurent Levy is a French physical chemist, inventor, and pioneer of nanotechnology and nanomedicine. He is the co-founder of the global biotechnology company Nanobiotix, and has served as*

*Chief Executive Officer since its inception in March 2003. He has authored more than 35 international scientific publications and owns several patents.*

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## PLEASE Help Support SPOHNC

*especially now, when so many  
feel isolated and alone.*



*SPOHNC's  
Chapter Support Groups and  
National Survivor  
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offer encouragement  
and hope  
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challenging times.*

*go to:  
**spohnc.org or call  
1-800-377-0928***

## DO choose masks that



**Have two or more layers of  
washable, breathable fabric**



**Completely cover your  
nose and mouth**



**Fit snugly against the  
sides of your face and  
don't have gaps**

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## Enjoy the Benefits

*Your Membership Matters... and Members Get More!*

This is one of two **complimentary** issues of “News from SPOHNC” you will receive in the next 12 months. Each April and October, we say “Thank You” by sending a newsletter to everyone. As part of a family of people that has been helped by SPOHNC, if you have ever called us, emailed us, or have ever been touched by SPOHNC in any way, the two complimentary issues you receive of **“News from SPOHNC”** are *SPOHNC’s way of saying thank you*. We are glad that you connected with us for help, support, and hope along your cancer journey, because ***Together We Heal.***

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SPOHNC’s 42 page

### **Product Directory**

products to help with the side effects of treatment including xerostomia (dry mouth), relief of mucositis, skin changes, dental care and the additional side effects of treatment.

Plus...

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

## Important News About Your Flu Shot

Now’s the time to get your flu shot. The flu shot is covered for people with Medicare from providers that accept Medicare or your Medicare plan. You can safely get a flu vaccine at your doctor’s office, pharmacy, or other local provider.

The flu can be very serious for people who are 65 years and older. A flu shot is your best protection from getting and spreading the virus. Getting the shot can help you stay healthy and, if you do get sick with the flu, your symptoms likely won’t be as bad or last as long.

All places offering flu shots should be following CDC guidance to ensure you have a safe place to get vaccinated. This includes that patients wear a face covering and maintain social distance in areas like waiting rooms. Visit [CDC.gov](https://www.cdc.gov) for more information on how to safely get your flu vaccine during the COVID-19 pandemic.



**Make a Difference. Give a Gift Today.**

## Congratulations to SPOHNC's Executive Director, Mary Ann Caputo!

We are very proud to announce that SPOHNC's Executive Director, Mary Ann Caputo, was honored on October 15th as one of Long Island Business News' Top 50 Women in Business on Long Island. This year's virtual celebration was attended by hundreds of friends, colleagues and family members, paying tribute to Long Island's top women professionals in the areas of business, education, government and nonprofit for their business savvy, influential work, mentoring and community involvement. This year marks the 20th Anniversary of celebrating women whose leadership and passion inspire us all.

Since 2005, Mary Ann has been a tireless advocate for families during what is often the most challenging time in their lives, guiding them through a cancer diagnosis, treatment and recovery. Since her appointment as Executive Director, Mary Ann has helped to develop new programs, published an array of resources for navigating oral, head and neck cancer, and helped to expand the number of support groups from 25 to more than 100 throughout



the country along with SPOHNC's National Survivor Volunteer Network mentoring program of more than 225 volunteers.

Her studies at City College and Pace University prepared her for a career in social services. Despite 10 years as a Finance Director at Revlon, Inc., her earlier residency as a social worker at Bellevue Hospital in NYC was the biggest game changer for her. Prior to joining SPOHNC, she put her energy into her family, raising her twin boys, Frank and Larry, and her daughter, Christina. She resides in Bayville, NY with her husband, Lawrence.

Today, Mary Ann is continuing her true calling. Helping others is a gift that keeps on giving and she feels blessed to be doing what she loves. In addition to her work at SPOHNC, Mary Ann is on the editorial board of the American Society of Clinical Oncology (ASCO), and on the EAB SPORE for Head and Neck Cancer at the University of Pittsburgh Medical Center.

When asked who inspires her, Mary

Ann confidently said "Nancy Leupold, Founder of SPOHNC, was an inspiration to me from the moment I met her. Her passion, work ethic and vision to help support cancer patients and their loved ones was incredibly inspiring and enriching. It is my privilege to be able to carry on her legacy and to develop and continue all of SPOHNC's programs, resources and publications for this cancer patient community. Here at SPOHNC, we enable cancer patients to overcome their initial feelings of helplessness and adopt a proactive attitude of survivorship. Together, We Heal."

Mary Ann also shared her thoughts about the best advice she received in business, and here's what she had to say... "Honesty, integrity and kindness have always been my model to emulate in my career, with my team, and staff members. Put simply, actions speak louder than words. I learned this watching my parents in their parenting skills, as well as their own careers. I was taught to make my own decisions, and learn from those decisions, challenging myself one day at a time."

Congratulations to Mary Ann, on this much deserved recognition!

## SPOHNC Chapter Innovations

During the COVID-19 pandemic, everyone is feeling more anxious and stressed than usual – especially oral, head and neck cancer patients. The extra stress of delayed appointments for treatment planning, treatment and follow up can cause anxiety that is beyond compare. COVID has brought many challenges to our country, and our world, but it has also brought innovation to cancer care, and cancer support.

Since all in-person meetings are on hold indefinitely, creativity has flourished, and our SPOHNC Chapter support groups are connecting in ways they never imagined they would. Many are keeping in touch individually by phone, some by email, and many of our groups have turned to the beauty (and sometimes the frustration!) of technology, to bring patients and survivors and their families together. Zoom, Webex and other platforms have become a way of life for many families and friends, and for our support groups as



well. For now, the added beauty of a virtual meeting is that it only has to be as close as your computer or your phone. Geography doesn't matter – and you can connect with others and still share the camaraderie that our SPOHNC Chapter support groups have become noted for.

To date, the SPOHNC Chapter Support Groups that we know are meeting virtually are in *Phoenix, AZ, Arroyo Grande and Los Angeles, CA, Winter Park, FL (coming soon), Evanston, IL, Baltimore, MD, Boston, MA, Minneapolis, MN, Lincoln, NE, Long Branch and Morristown, NJ, Middletown, Southampton and Syosset, NY, Southern Oregon, Lancaster and Philadelphia, PA, and Dallas, TX (may be coming soon).*

If you are a SPOHNC Chapter Facilitator or attendee and your meetings have converted to a virtual platform and you're not listed here, please contact SPOHNC to let us know so we can add you

to the list and share the news with callers who contact SPOHNC seeking support.

If you are a SPOHNC Chapter Facilitator or Co-Facilitator and you would like to find out about how to set up a virtual meeting, we are happy to help! Contact the SPOHNC national office at 1-800-377-0928. Many of our groups that are already "zooming" are also happy to coach you along your way, so connect with SPOHNC to find out more. If you're looking for a meeting, contact SPOHNC! Let SPOHNC know how we can help you to stay connected.

SPOHNC wishes to thank our Chapter Facilitators and Co-Facilitators for all you do. Each month, you help and support the patients and families in your group, bringing them together to share questions, concerns, good news and life in general. Our SPOHNC Chapter support groups become like extended family for many who attend, and for the Facilitators as well. Thank you on behalf of SPOHNC, to each of you for providing help, and hope, because

***"Together We Heal"***

## Time for Sharing... *My Story*

In 1997, after years of trying to figure out how to change careers (from technical project manager to school teacher) without disrupting my family, I left the decision up to God. Within four months of that surrender, I received certification as a high school math and physics teacher, and got hired to teach at a vocational high school in rural western New York State. It was a good move, and one I was happy about. Jump ahead to 2005, the first day of school...the Tuesday after Labor Day. I was getting ready for work and shaving when I noticed a bump in my neck.

I remember saying to myself "that was not there the last time I shaved." By Friday of that week, I saw my family doctor, and he prescribed an antibiotic. He told me that if I did not see any change in the next 10 days, to let him know. At the end of the 10 days, there was no change, but he reassured me



that there was no reason to postpone a long planned trip for late September. I set off for a 10-day 'Water Journey' adventure in the southwestern U.S. When I returned in early October, the 'bump' was still there.

Thus, began a series of examinations and tests that lasted five weeks with the conclusion being 'we think it is a cancerous growth but we are not really sure.' Finally, my family doctor called my wife (Amrit) and me in for a meeting. He said, "the only way we are going to know for sure what this is, is to cut it open and test it." A biopsy surgery was scheduled for November 11 at University of Rochester (U of R) in Rochester, NY, about 100 miles from home.

During the period from the beginning of October until the scheduled surgery, I had been having many 'peer-counseling' sessions to express/discharge my feelings during this period of uncertainty and testing with no conclusive results. I highly recommend this type of counseling. I discovered it in the late 1980's and have been using it ever since. The formal name is Re-Evaluation Counseling and you can find

more information about it at their website, [www.RC.org](http://www.RC.org).

Finally, November 11th came, and I had the surgery...the results were in. I had Stage-IV Squamous Cell Cancer of the throat. It was in my tonsils. Later that night, while still in recovery, I remember a nurse saying to me that I looked 'pretty good' for a person who has just learned that they have Stage-IV cancer. I smiled and thought 'this is a benefit of all the counseling sessions I had leading up to this point.'

A week or so later I saw the surgeon who stated "You do not want me to do surgery. If something goes wrong, you will either be dead or a vegetable." He also said, "you should just plan on taking a year to deal with this." I thought, that is not in my plans. Once again, I found myself giving things over to God. That led to an appointment with an oncologist, with the plan that they would take the lead.

A couple of days later I saw a local oncologist, got their thinking, and then went back to U of R to see an oncologist for a second opinion. The U of R oncologist told me that U of R is a large cancer center and many people come here for treatment because it is in the city, but truthfully, they could go anywhere else and get the treatment they need. Then she looked directly at me, and pointed her finger at me and said 'You need to come here because with your condition, you will not get the treatment you need elsewhere.' She then laid out her proposed treatment plan: 70 Radiation sessions, and some chemotherapy. The treatment would last seven weeks and I would need to re-locate to Rochester for the duration of the treatment. Then she laid out the pre-requisites for treatment (the treatment will not begin unless all are done well in advance) of starting treatment: Remove teeth numbers 15, 18 and 19 and have a feeding tube installed. I remember walking out of that meeting, thinking and

sharing with Amrit, "This is NOT what I expected!" I had a daunting list of things to take care of. I started with making sure my last day at school for that school year coincided with the start of Thanksgiving break. I made a trip to Massachusetts to visit all my family before the treatment began. By then, I was having headaches, and the tumor had grown large enough to start deforming my face. I used the next month for meeting all the treatment pre-requisites.

On January 1, Amrit and I relocated to Hope Lodge in Rochester. This became our home for the next seven weeks. Treatment began on January 2, 2006. Hospitalized the first week of treatment; I had four days of chemotherapy, and radiation sessions twice a day, five days a week, with weekends off. I remember my first radiation treatment – lying on the table with my head held secure to the table and looking up at the machine, wondering what is coming next. Amrit remembers sitting outside the room and seeing the light "radiation in use" come on. When the light went off, she said she stopped holding her breath, and wondered how I was doing.

Amrit stayed at Hope Lodge, and by my side for the first two weeks, then my two older brothers and my two children (both then in their late twenties), came for a week and shuttled me back and forth from the Lodge to the hospital while Amrit went home to do some work at her Hospice job. To this day, I am very grateful for their help and support. I remember vaguely in the middle of the third week or so, telling my oldest brother that I didn't think I wanted to go back for an afternoon treatment and his response was something like, "OK, I hear you, and we are leaving in 15 minutes." On it went.

Early in the treatment, I remember sitting with Amrit and the nutritionist discussing how many daily calories I would need via the feeding tube, once I had to start using it. The agreement was ~ 2,400 calories per day. When the radiology doctor inserted the tube, he chose to have it end not in my stomach, but in the beginning of my small intestine. This minimized the threat of nausea and vomiting. It was a good choice. Once I started using the feeding tube, the daily caloric intake was increased to prevent

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weight loss. Final daily caloric input was in the range of 4,200 calories. The pump that fed the liquid through my feeding tube ended up running about 20 hours per day. And my daily routine was to get up in the morning and go to my morning radiation session, return to the Lodge, take a nap, go back for afternoon treatment, return to the Lodge, hang out for a little bit and then back to bed. My body was obviously using a lot of energy internally.

One of my greatest blessings during this time was the co-counselors I knew from the greater Rochester area. They volunteered to come visit me at Hope Lodge and just listen to me share my feelings, cry, or whatever. It was a great, ongoing conduit for letting my emotions out without burdening my family with them. God, friends, family, medical staff and co-counselors...I was never alone on this journey.

February 24, 2006 was my last radiation treatment. It was a Tuesday. I was exhausted, and Amrit and I decided to stay at Hope Lodge until Saturday so we could just rest and accumulate enough energy for the trip home.

Next phase... I started the road to recovery. That involved resting, sleeping and pain and symptom management. I slowly regained energy, got off the feeding tube, relearned to swallow and learned to eat again. I gave over to the process of letting my body heal itself. At the time, we were living way out in the country and had a lake nearby to swim in. By the end of the summer, I was back in the water. All the follow-up tests were negative, the cancer was gone and it has not returned. I was and continue to be very grateful for this outcome.

At the start of the 2007 school year, I went back to work. The first month was a challenge because of the steep change in activity. In October, I remember playing a game of basketball in a gym class and realized that finally I felt like I was back and ready for whatever came next.

Before my cancer diagnosis and treatment, I had been studying with a Native American teacher and one of the things that resonated with me was the Medicine Wheel. It has four directions: E, S, W & N, and each of the directions corresponds to a facet of our humanness: Mental, Physical, Emotional and Spiritual. To have a 'smooth' journey, it helps if the spokes of

our individual Medicine Wheel are equally long and equally strong. I had come to the realization that I needed to strengthen my North, Spiritual spoke. I began in earnest during my treatment and have continued ever since. It remains a very interesting and positive part of my journey.

In the ensuing years after my treatment, life returned to 'normal'. I lost tooth number 20 in 2011. I had been seeing a vascular surgeon to monitor my carotid arteries as the left one was significantly affected by the radiation treatment. In late 2014, one day when Amrit and I were in the car and I was driving, I noticed a distinct change in my vision in my left eye. Amrit took over driving that day. It turns out that my left carotid artery went from being significantly blocked to almost completely blocked in a very short time. I had been waiting for it to reach the threshold that signified it was time for an operation to clear it out.

That threshold came and went, and made it inappropriate to do the operation. I would live without a functioning left carotid artery. In March of 2015, I had an operation to clean out the right carotid artery as it had narrowed, and was the only one I had working. And, it still is. It has not limited the active life that I still lead. Our bodies are amazing!!

In the fall of 2015, I began to notice swallowing issues and started seeing a speech pathologist. I believe seeing the speech pathologist slowed down the rate of my decreasing swallowing function. Eventually, it became clear that I was aspirating food into my lungs as evidenced by frequent lung infections. I knew I needed a different approach. It finally became clear that I needed to have a feeding tube installed so that I could increase my calorie and nutrition status without constantly aspirating my food. That happened in May of 2018. The result is a tremendous improvement in my health and stamina. I still eat small amounts of food and drink liquid(s) for enjoyment.

I had a hearing aid prescribed in 2001 for one ear due to damage caused by both genetic history and exposure to noise in my earlier career in the navy. I used it for about three years and stopped using it. Right before I started my cancer treatment in 2006, I had my hearing tested, and after my treatment, I had it retested. The retest showed a significant loss of hearing function

that was a result of my treatment. One of the chemotherapy drugs that I took was Cisplatin, which is ototoxic for some people, like me. Therefore, I got new hearing aids for both ears. Over time, my hearing function continues to degrade, and the hearing aids need adjustment so that I can keep on keeping on.

In the fall of 2018, Amrit and I moved into town. We are happy in our new home. It is now May 2020 and the COVID-19 Virus is running rampant and disrupting the world and life as we know it. The doctor who said back in 2005, 'you should just plan on taking a year to deal with this' was correct, even though I didn't think so at the time. In February of this year, Amrit, a friend, and I spent the month in the Dominican Republic. My biggest challenge was figuring out how to take a month's worth of feeding tube nutrition and supplies with us. It happened, but that is another long story of trusting that things work out. Amrit and I have undertaken a project to turn our front yard into a sustainable, neighborhood 'food forest' so that we can help feed the world as it has fed us in so many ways. As Amrit says, "the 'Garden of Eden' still exists if we only allow it to." As the weather continues to warm up, there is no shortage of things to do.

The COVID-19 virus will run its course and life will go on and it will not be the same as it was before. Just like hearing you have Stage-IV cancer and living through the treatment and resuming life afterwards and constantly adapting and adjusting to the collateral damage caused by the treatment. Life goes on and I am sooooo GRATEFUL.

~ Mark Kilmartin  
markkilmartin3@gmail.com

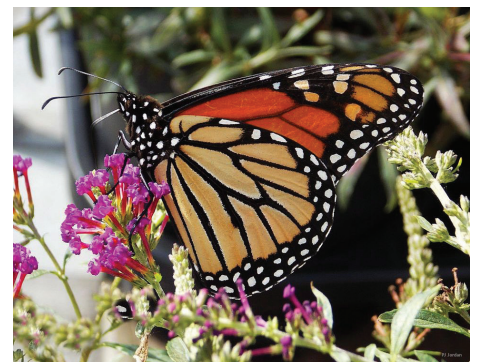


photo courtesy of PJ Jordan,  
NSVN Volunteer and awesome photographer

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## Head and Neck Cancer News

### *Do you need a vitamin D supplement during the COVID-19 pandemic?*

*By Heather Alexander – courtesy of MD Anderson Cancer Center*  
Your body depends on vitamin D. And one of the ways to get it is by being outside. That's because the sun's UV rays activate vitamin D production.

So if you're staying indoors more during the coronavirus (COVID-19) pandemic, you might be wondering if you need to take a vitamin D supplement.

To find out, we talked with Susan Chon, M.D., a dermatologist in MD Anderson's Cancer Prevention Center.

#### **Why do you need vitamin D?**

Vitamin D is most commonly linked to bone health and keeping your bones strong. But that's not all it does. Vitamin D also:

- reduces inflammation
- supports your immune system
- strengthens muscles and reduces spasms and cramping
- helps with glucose metabolism
- regulates cell growth

"Vitamin D is really critical for the body because it has all these different jobs," says Chon. "If your vitamin D level is low, it can make you more susceptible to osteoporosis, cancer and chronic diseases like heart disease, depression, diabetes and weight loss." For cancer patients, vitamin D may also affect survival rates.

"There is definitely some interesting research that having a healthy level of vitamin D may actually help you live longer," says Chon.

#### **If you're indoors more during the COVID-19 pandemic, will it affect your vitamin D level?**

If you're staying inside more during the coronavirus pandemic, your vitamin D level may drop.

But it's hard to say if the sun was providing you with the right amount, even before COVID-19, Chon notes.

"While you do get some vitamin D from your daily comings and goings outside, it's

not enough," she says.

UV levels differ across the country, and you might not process it well depending on your age and the pigments in your skin.

"Sunlight is just one way to get vitamin D, and it's certainly not the most efficient," says Chon.

It's more efficient to get vitamin D from your diet. You can get vitamin D in many foods like salmon, eggs, yogurt, milk, juices and even mushrooms.

If you try to boost your vitamin D by spending more time in the sun, you may also damage your skin and increase your risk for skin cancer.

"Some people are spending more time outdoors in their backyard, or exercising in their neighborhood because of COVID-19, and they may be increasing their overall sun exposure," says Chon. "If you're going to spend more time outdoors, it's important to take more care with your skin protection routine."

#### **Should you take a vitamin D supplement during the COVID-19 pandemic?**

Some people may still struggle to get enough vitamin D through diet. But talk to your doctor and get your vitamin D level checked at your annual physical to determine if you really need to take a supplement.

"There are some early findings that suggest that those patients who have optimal levels of vitamin D may decrease their risk of contracting COVID-19 and the severity of the disease if they contract it," says Chon. "But more research is needed to understand the connection between COVID-19 and vitamin D."

If your doctor does recommend a supplement, they'll tell you how much to take based your age and other factors. Be sure to follow this advice. It is possible to get too much vitamin D, which could increase levels of calcium in your blood, leading to bone and kidney issues.

#### **Do cancer patients need a vitamin D supplement?**

If you are a cancer patient, your oncologist can talk to you about supplements. "Vitamin D supplements are relatively safe, but there

are a few interactions with other medications that can occur," says Chon.

"The best thing to do is to get a lab test from your doctor, and they may recommend that you take a supplement," says Chon. "People should know their vitamin D level before taking any action."

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*"In the meantime, sit tight. Be of good cheer. Love the ones you're with. Call or write or participate in our private Facebook group if you can, we'd love to hear what you're doing to stay sane. And if you're not feeling sane at all, please - especially! - reach out so we can commiserate."*

### **TOGETHER WE HEAL!"**

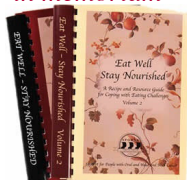
*~ Bill & Linda Clyne,  
SPOHNC GREENVILLE, SC  
Chapter Facilitators*



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***for Coping  
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Nancy E. Leupold, Founder  
in memoriam



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**Outstanding October Comfort Foods 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*

***Easy Shepherd's Pie (from Volume Two)***

1 lb. leftover minced lamb or minced, cooked beef  
1 onion, finely chopped  
4 Tbsp. butter  
½ c. beef broth  
1 tsp. Worcestershire sauce  
Salt and pepper to taste  
4 c. mashed potatoes  
½ c. grated Cheddar cheese



Melt butter in saucepan and saute beef or lamb with diced onions. Do not drain. Add beef broth and Worcestershire sauce to the meat and onions, stirring until the juices are thoroughly mixed and meat is heated. In an 8 x 8 baking dish, spread the beef and onions. Spread the mashed potatoes evenly over meat. Distribute cheese on top of potatoes. Bake at 400 degrees until cheese is melted and pie is bubbling. Serves 6. 522 calories/serving.

*~ Hannah Swenson, NY*

***Pumpkin Chiffon Pie - (from Volume One)***

1 envelope Knox gelatin  
¼ c. cold water  
½ c. milk  
¾ c. sugar  
3 eggs  
1 ¼ c. pumpkin  
½ tsp. ginger  
½ tsp. nutmeg  
½ tsp. cinnamon  
½ tsp. salt

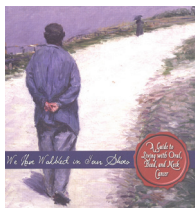


To slightly beaten egg yolks, add ½ c. sugar, pumpkin, milk, salt and spices. Cook until thick in double boiler. Pour cold water in a dish and sprinkle gelatin on top of water. Add to hot mixture. Mix thoroughly and cool until mixture begins to thicken. Beat egg whites (3) and remaining ¼ cup sugar until stiff. Fold into thickened pumpkin mixture. Pour into baked pie shell. Chill. Top with whipped cream. Yields 8 servings. 262 calories/serving.

*~ Bette D., AZ*

***Coming Soon!  
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***We Have Walked In Your Shoes:  
A Guide to Living With  
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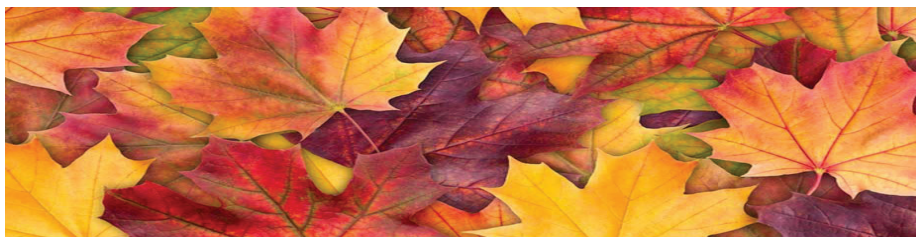


by Nancy E. Leupold  
& James J. Sciubba, DMD, PhD

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## Head and Neck Cancer News

### *A promising breath-test for cancer*

October 5, 2020 - by Flinders University  
- The global quest to use a person's breath analysis for rapid, inexpensive and accurate early-stage testing for cancer and other diseases has taken a leap forward.

In a new paper in the *British Journal of Cancer*, Flinders University researchers have reported significant progress in developing a method to test exhaled breath profiles which accurately differentiate head and neck cancer from non-cancer patients.

The Australian researchers collected breath samples from 181 patients suspected of having early-stage head and neck squamous cell carcinoma (HNSCC) before any treatment began.

"We sought to determine the diagnostic accuracy of breath analysis as a non-invasive test for detecting head and neck cancer, which in time may result in a simple method to improve treatment outcomes and patient morbidity," says lead researchers Dr. Roger

Yazbek and Associate Professor Eng Ooi.

Worldwide, head and neck cancer accounts for 6% of all cancers, killing more than 300,000 people per year globally. Tobacco, alcohol and poor oral hygiene are known major risk factors for this cancer.

A surge in human papilloma virus (HPV)-associated head and neck cancers is seeing these cancers affecting a much younger population, the researchers say.

Current therapies are effective at treating early-stage disease, however late-stage presentations are common, and often associated with poor prognosis and high treatment-related morbidity.

In the Australian study, a selected ion flow-tube mass spectrometer was used to analyze breath for volatile organic compounds. Using statistical modeling, the Flinders researchers were able to develop a breath test that could differentiate cancer and control (benign disease) patients, with

an average sensitivity and specificity of 85%. Diagnosis was confirmed by analysis of tissue biopsies.

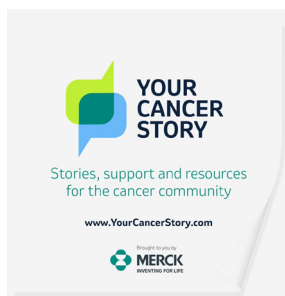
"With these strong results, we hope to trial the method in primary care settings, such as GP clinics, to further develop its use in early-stage screening for HNSCC in the community," says co-lead author Dr. Nuwan Dharmawardana.

## Your Cancer Story

You may remember SPOHNC's collaboration and program with Merck, entitled *Your Cancer Game Plan*. In this partnership, we worked with Jim Kelly, head and neck cancer survivor and Buffalo Bills alumni, to raise awareness and help provide resources and information for those affected by the diagnosis and treatment of oral, head and neck cancer. We are proud to announce our continued our partnership with Merck, which has now expanded to also include *Your Cancer Story*.

*Your Cancer Story* is an online platform developed by Merck and the cancer advocacy community that provides information and support to people throughout every stage of the cancer journey, from diagnosis to survivorship. The website's resources include tips on how to get important information about cancer care, ways to

better communicate with loved ones and healthcare teams, strategies to cope with the emotional challenges of cancer, and inspiring stories from people who have been there before. Learn more by visiting [YourCancerStory.com](http://YourCancerStory.com) and find support to help you feel your best, inside and out.



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what you are doing.  
It is so meaningful  
to so many.”***

*~ Bonnie Martin-Harris, Ph.D.,  
CCC-SLP, BCS-S  
Member of SPOHNC's MAB*





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