

NEWS FROM S.P.O.H.N.C



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

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S.P.O.H.N.C
A PROGRAM OF SUPPORT FOR
PEOPLE WITH
ORAL AND
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Proton Therapy to Reduce Side Effects in Head and Neck Cancer

Brian C. Baumann, MD; Kelly M. MacArthur, MD

Head and neck cancer patients require specialist care from surgeons, radiation oncologists, and medical oncologists. Patients with larger or more advanced disease who are treated with surgery will frequently receive post-operative radiation therapy with or without chemotherapy. For patients not treated with surgery, radiation therapy, sometimes used in combination with chemotherapy, is a common treatment for more advanced disease. Cure rates have improved, but the side effects of treatment, both during therapy and in the years after therapy is completed, can be significant. In addition, an increasing proportion of head and neck cancer patients are younger and healthier and present with human papilloma virus (HPV)-associated cancers, which generally have a better prognosis. Reducing side effects during treatments and in the months to years after treatment is of critical importance for patients. There have been a number of recent strategies to reduce side effects for head and neck cancer patients in the realm of surgery, systemic therapy, and radiation therapy. We will discuss several recent strategies to reduce radiation therapy side effects and focus on one particular development in radiation oncology: the use of proton therapy to reduce side effects in head and neck cancer patients.



Improvements in radiation therapy strategies

Efforts to reduce the toxicity of radiation for head and neck cancer patients have included the development and refinement of intensity-modulated radiation therapy (IMRT) to limit dose to the

*This issue of
“News from SPOHNC”
is dedicated
to SPOHNC’s Founder,
Nancy Leupold,
in memoriam...*



surrounding normal tissues. There are also ongoing clinical studies in patients with HPV-positive head and neck cancer to assess the feasibility of delivering a lower dose of radiation and/or shrinking the size of the target, all in an effort to reduce collateral damage without sacrificing cancer-control outcomes. For example, there is promising preliminary data that for HPV-positive patients, the radiation dose can be reduced for selected patients without reducing effectiveness. Although current guidelines say that these patients should be treated with the standard, higher doses of radiation, those guidelines may change in the near future as more data becomes available. For other patients, there is growing awareness that it may be possible to avoid radiation to the lymph node regions of the neck on the side opposite the tumor, based on recently published research from Washington University in Saint Louis. Other studies have shown that patients may be able to avoid receiving radiation to the site of the primary tumor if the tumor was small and fully resected. It is important to review with healthcare providers to see if any of these toxicity-reducing strategies are appropriate for an individual patient. While they may be appropriate for some, they are not appropriate for all patients.

Proton Therapy as a technique to reduce radiation side effects

One particularly exciting development in the treatment of head and neck cancer patients is the expanding role of proton therapy as an alternative radiation treatment modality. Conventional x-ray radiation is used to treat >99% of patients with head and neck cancer in the U.S. and Europe, with most head and neck cancer patients receiving the most sophisticated form of photon radiation: IMRT. IMRT is an excellent treatment modality that allows doctors to safely escalate the radiation dose to the target while greatly minimizing radiation dose to the surrounding normal tissues, including the jaw, salivary glands, and spinal cord, among others. As good as IMRT has become, IMRT still relies on x-ray irradiation, which deposits radiation as the beams enter the body, as it hits the target, and as it exits the body. Proton therapy, by contrast, allows the radiation beams to treat the tumor target without

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Nancy E. Leupold, MA
In Memoriam

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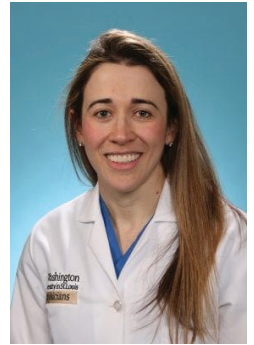
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exit dose extending beyond the target and into the healthy tissues. There has been great enthusiasm recently over the potential role of proton therapy to reduce side effects in head and neck cancer, because as many would say, head and neck cancers are located in “prime real estate” in the body. By reducing radiation dose to normal structures, proton therapy may allow doctors to deliver a higher dose of radiation more safely, which may in turn improve cancer outcomes and quality of life.



Proton therapy: The problem of cost and access

One of the challenges of proton therapy is that the upfront costs associated with establishing a proton center are much higher than those for traditional radiation centers. Additionally, maintenance costs for proton therapy are higher and more technical expertise is required. Not surprisingly, the cost of proton therapy passed on to the insurance company can be significantly higher. In addition, most head and neck cancer patients require treatment plans that are so complex that only next-generation proton therapy techniques, called pencil beam scanning, are robust enough to create feasible radiation treatment plans for these patients. Lastly, access to proton therapy remains an issue. While proton centers have proliferated over the last few years, there are still limited facilities in the country, with many larger cities not serviced with a proton machine. The limited availability and higher cost remain important barriers limiting access to proton therapy.

What is the available data for proton therapy for head and neck cancer?

Proton therapy has a long track record for the treatment of rare base-of-skull tumors called chordomas. These tumors require very high doses of radiation to cure and are situated in very sensitive areas close to the brainstem and critical cranial nerves. Proton therapy has allowed for improvements in the treatment of chordomas by allowing an increased dose to be delivered to these tumors, improving outcomes for patients.

What about proton therapy for patients with more run-of-the-mill head and neck cancers? Several retrospective studies have been performed showing comparable cancer control outcomes for head and neck patients treated with protons, with most showing significant reductions in radiation dose to normal tissues and decreased probability of side effects associated with proton therapy. Proton therapy has been shown to reduce the risk of dry mouth, pain/difficulty with swallowing, mouth sores, and taste changes, among other side effects. Proton therapy may also help patients to avoid the need for a feeding tube during their treatments.

A recent study published in *JAMA Oncology* in December 2019 found that for all patients treated with combination chemotherapy and radiation therapy for any cancer at the University of Pennsylvania, proton chemo-radiotherapy was associated with a significant, two-thirds reduction in the rate of severe side effects that lead to unplanned hospitalizations compared to photon chemo-radiotherapy.

This study included 1483 patients who were followed
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prospectively for toxicity outcomes. Of the 1483, 437 patients (29%) had head and neck cancer. While the cohort of head and neck patients receiving proton therapy was relatively small, these results demonstrated a similar benefit in the head and neck cohort to what was seen in the overall study group.

Clinical trials are ongoing to compare proton vs. photon therapy for head and neck cancer, with perhaps the most prominent trial taking place at MD Anderson (Principal investigator: Dr. Steven Frank). Preliminary results from this clinical trial have demonstrated an important reduction in toxicity with proton therapy. Additional data from this and other clinical studies are eagerly awaited.

Is proton therapy right for you?

In our opinion, proton therapy is a very exciting treatment with tremendous promise for patients with head and neck cancer because the target can be treated with the same dose of radiation, but spare the surrounding structures more effectively, reducing the risk of serious side effects both during treatment and in the months to years after treatment. More research is needed to compare proton versus photon therapy for head and neck cancer and to better identify the patients who are most likely to benefit from proton therapy. There are certainly patients with head and neck cancer where proton therapy may not be possible, due to extensive metal artifact near the target that would interfere with the proton particles (e.g. extensive dental work or spinal fusion surgery), or because of challenges in the size/dimensions of the target volume. Insurance coverage also remains a challenge, since many private insurers do not cover proton therapy for head and neck cancer.

While proton therapy may be worth exploring for some patients, it is important to emphasize that IMRT is an excellent treatment with a long track record in head and neck cancer and is currently considered the standard-of-care. In our opinion, the future looks bright for proton therapy for head and neck cancer as a way to reduce side effects and improve patient quality-of-life.

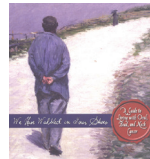
Editors Note: Dr. Brian Baumann is an assistant professor of radiation oncology at Washington University in Saint Louis and an adjunct assistant professor of radiation oncology at the University of Pennsylvania. He is an expert on the comparative effectiveness

of proton vs. photon therapy, and his research has been reported on extensively in the medical and national lay press. He specializes in the treatment of rare head and neck cancers (Merkel cell carcinoma and sarcoma) and genitourinary cancers.

Dr. Kelly MacArthur is a Mohs-college fellowship-trained Mohs surgeon and assistant professor of dermatologic surgery at Washington University in Saint Louis. She is an expert on cutaneous skin cancers of the head and neck and has served on the board of the American Society for Dermatologic Surgery.

***We Have Walked
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*by Nancy E. Leupold
& James J. Sciubba, DMD, PhD*



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April Oral, Head and Neck Cancer Awareness Month

April is Oral, Head and Neck Cancer Awareness Month. While many previously planned awareness activities had to be cancelled or postponed, due to the COVID-19 crisis across our country and in our world, several still took place, and they deserve special recognition this year. Newly diagnosed patients, survivors and their families can feel good knowing that awareness was still top of mind across the U.S., and especially in several cities across the country.

Traditionally for the past several years, Niagara Falls has lit up the night sky on April 1st to recognize and join in raising awareness of oral, head and neck cancer. This year was no different! Thank you to the Niagara Falls Illumination Board for this great honor as we observed the live video of the Falls lit up in our SPOHNC colors from 10pm til almost 10:30pm!



If you live in or near New Orleans, LA, then you are surely familiar with the Mercedes-Benz Superdome. The dome is the home of the New Orleans Saints, and hosts many sports events, and it is also a beacon of light at night. This year, for the first time ever, the Superdome was lit in the colors of SPOHNC on April 1st, to join us in raising awareness! Thank you, NOLA, for helping SPOHNC through this unique opportunity to share our colors with the beautiful city of New Orleans!

This year's additional awareness recognition came from someplace very unique, and very well known if you live in Minneapolis, MN. The I-35W Saint Anthony Falls Bridge crosses the Saint Anthony Falls on the Mississippi River in Minneapolis, Minnesota. It is a



beautiful bridge, reconstructed after a terribly tragic collapse in 2007. The bridge is a symbol of hope, and what better way to share hope, than by having the bridge lit up in our SPOHNC colors in April. So, on April 4th, from sunset to sunrise, the beautiful bridge

was lit up in burgundy and white, raising awareness and sharing hope with the city of Minneapolis and its surrounding areas. Thank you to the Minnesota DOT for this wonderful privilege!

During April Awareness Month SPOHNC also launched a campaign together with The THANC (Thyroid, Head and Neck Cancer) Foundation supporting our unified missions. You can still support the #stayhome message with the purchase of our graphic tees or mugs. It continues to be a scary time for patients who must go through treatment right now. Cancer treatment can't simply be put on pause.



#StayHome to help protect essential workers, medical staff, patients and survivors. Purchase your t-shirts or mugs at <https://j.mp/2XShpAb>.

We know many of you had to postpone your awareness events and activities. Let us know about all that you're planning and doing when you reschedule so that we can help you to continue to raise awareness.

Send us your photos and stories, for inclusion in a future issue of "News from SPOHNC."

SPOHNC will continue to be there for you as we slowly return to our "normal daily lives."

Let's all continue to raise awareness of oral head and neck cancer, not just in April but every day, because...

**TOGETHER
WE
HEAL!!**



Nancy Edith Leupold... In Memoriam

"It is time for us to stand and cheer for the doer, the achiever, the one who recognizes the challenge and does something about it."
– Vince Lombardi



It is with heavy hearts and the deepest sadness, that we share with you the news of the passing of SPOHNC's Founder, Nancy Leupold. Nancy passed away on January 26th. She was 80 years young. Nancy E. Leupold founded SPOHNC in 1991 after her diagnosis and treatment for oral cancer in 1990. She discovered that there was no support for those seeking someone to connect with both during and after treatment...someone to help her in dealing with the questions, worries and fears associated with the diagnosis and treatment of this devastating disease.

Nancy was a pioneer, and a trailblazer - she had a laptop and an idea, when she started SPOHNC, in an office in her home. Her legacy began with one support group on Long Island. Nancy's tenacity, determination and endless hours of hard work and devotion enabled SPOHNC to provide hope to those who were affected by the diagnosis and treatment of oral, head and neck cancer. That journey of hope continues today as SPOHNC is entering its 30th year of support.



Nancy dedicated more than 25 years to SPOHNC, all the while hoping that research would bring better and improved treatments. She held the first SPOHNC Chapter support group meeting on September 10, 1991. Nine people showed up and sat in a circle. None of them knew each other, but they knew they

had something in common. One by one they shared their stories and began to recognize similarities between them. Sharing their experiences was great "therapy" and by the end of the evening, nine strangers had become friends. Everyone finally felt a lot less alone. Nancy's perseverance and compassion has enabled SPOHNC to grow to the more than 100 Chapter Support Groups that exist today, along with the National Survivor Volunteer Network of more than 225 survivor and caregiver volunteers. Nancy also created and developed, with James J. Sciubba, DMD, PhD, President of SPOHNC, the many publications that are welcomed by our SPOHNC family. She is revered in the head and neck cancer community for her vision and hard work.

Nancy will be remembered by her Board of Directors, Medical Advisory Board, colleagues, survivors, caregivers and volunteers for SPOHNC as an amazing woman, who led by example, always seeking new ideas and additional ways to support oral, head and neck cancer patients and survivors.

She was an inspiration to all who encountered her. Some of those people shared sentiments with her SPOHNC family...

SPOHNC Executive Director, Mary Ann Caputo, shared her touching, heartfelt tribute to Nancy, who was her fond friend and mentor... "She truly believed that "together" each of us has the ability to help others heal, go forward, and maintain a better quality of life. I was especially proud to have been touched and enriched by working alongside Nancy for many years. Nancy reached thousands and she will continue to do so through her legacy."

"We all owe Nancy a great deal of gratitude for creating this wonderful organization that has helped so many survivors of oral, head, and neck cancers. Nancy was truly a remarkable person and will be missed." ~ Frank Marcovitz – Survivor and SPOHNC Chapter Facilitator

"What an incredible legacy she left. Literally a bright light shining forth for generations to come." ~ Anne Wesp – Caregiver

"We are all fortunate to be able to be a part of the organization that she created. Nancy was one of those wonderful people who left things in a better state than that in which she found them. May her memory be for a blessing." ~ David M. Brizel, MD – SPOHNC Medical Advisory Board

"I have known Nancy since I took care of her mother, Hannah, in Nancy's home in the very

beginning of SPOHNC in 1991/92. I also took care of their cat, Tookie. I started working with SPOHNC in 2002 when Nancy asked me about helping with the newsletter mailing. I still manage the mailing of the newsletters today, labelling, sorting and bringing the mailing to the post office. It's something I enjoy doing and it helps SPOHNC. Nancy was a wonderful woman...you couldn't ask for anyone better. She was kind, dedicated and she did a wonderful thing by starting SPOHNC. I loved her" ~ Janet Fried – SPOHNC friend & staff member

"Nancy was one of a kind. Nancy through her own suffering recognized the need for a support group for patients who had cancer of the oral cavity and other sites in the head and neck.

She provided great leadership propelled by her passion for helping patients avoid the negative experience she had gone through following the treatment of her cancer. We miss Nancy with her



extraordinary capacity for hard work and her compassion for the patients who suffered from the ravages of cancer of the head and neck. We on the Board of Directors of SPOHNC and the patients who we support are fortunate indeed to have Mary Ann Caputo, who worked with Nancy, and has succeeded her as Executive Director. She has

done an outstanding job in leading our organization." ~ Eugene Myers, MD, FACS, FRCS Edin (Hon) – SPOHNC Board of Directors

Throughout the years Nancy was honored by many medical organizations. In 1992 she received a letter of recognition from President and Mrs. George H.W. Bush for her many accomplishments and making a difference in the communities of this great nation.

Nancy had an endless energy and drive to ensure SPOHNC was there for each and every patient. SPOHNC has brought people "together" to help support patients, survivors and their loved ones and will continue to do so through Nancy's legacy and the team she always called her second family. She was someone you could talk to, learn from, laugh and cry with, share a hug with, and someone who had a zest for life and learning. Her accomplishments were an inspiration to everyone, especially those who had the opportunity to work with her. We will all miss this wonderful woman of grace, courage and strength. She was a bright and shining beacon of hope for head and neck cancer patients, survivors, caregivers and their loved ones.

"It's been said that the best prayer of all is one of gratitude, and today we all share in a prayer of thanks to Nancy." ~ Richard Boucher – Survivor

***"She was a force. We didn't lose a legend – we lost THE legend. She made things better for thousands and their loved ones – that is a legacy which few could ever match."* ~ David Myssiorek, MD, FACS – SPOHNC Medical Advisory Board**



Support for People with Oral and Head and Neck Cancer, Inc. is grateful for the generosity of its partners and contributors. Thanks to their support, SPOHNC is able to maintain and extend its programs of education and support to cancer survivors, their families and friends. With sincere appreciation to all.

2019

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Merck discovers, develops and provides innovative products and services that save and improve lives around the world.

Nanobiotix designs and manufactures nanoparticles that safely enhance the efficacy of radiation therapy in the treatment of cancer. With this approach, our ambition is to benefit millions of patients who receive radiation therapy by improving the efficiency of radiation in tumor cells without increasing the dose received by surrounding healthy tissues.

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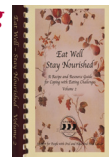
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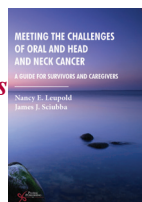
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of our lives. Our deepest gratitude goes out to each and every healthcare professional, first responder and essential worker for all of your tireless hours of hard work and dedication. Leaving your families so you can take care of ours means more than we can express in words. We appreciate you beyond measure!!

COVID-19 Q & A

The American Society of Clinical Oncology (ASCO) and the National Coalition for Cancer Survivorship (NCCS) are working together to provide information about how coronavirus 2019 (COVID-19) could potentially affect the health and cancer care of people diagnosed with cancer. Below are answers to cancer survivors' frequently asked clinical questions about COVID-19 from ASCO Chief Medical Officer and Executive Vice President Dr. Richard Schilsky.

Will anything change with my cancer-related medical visits?

Most hospitals and clinics have changed their visitation policies. Before heading to your medical appointment, check with the clinic or hospital for their current visitor policy. Your cancer care team may switch some of your appointments to telemedicine through video conferencing or by telephone.

Does having received chemotherapy or radiation in the past raise your risk for getting COVID-19 or having a more serious course of illness?

To date, no evidence is available to suggest that any cancer treatments raise your risk for getting COVID-19 any more or less than anyone else who is exposed to the virus. There is some evidence that patients with cancer may experience more serious COVID-19 infection if they acquire it, likely because cancer and cancer treatment can contribute to weakened immune systems which can then lead to a reduced ability to fight off infections.

If a person is about to start cancer therapy should they consider postponing?

Patients should talk with their treating oncologist about the risks of postponing treatment versus the potential benefit of decreasing their infection risk.

I am a survivor of cancer who receives regular scans/imaging/tests to detect potential recurrence. Should I keep getting this testing?

In general, as recommended by the CDC, any clinic visits that can be postponed without risk to the patient should be postponed. This includes routine surveillance visits to detect cancer recurrence. If you develop a new symptom that might indicate cancer recurrence you should contact your cancer care team and not wait for the next scheduled evaluation.

If I have a delay in care, or need to change providers to receive care, is there anything I should do with respect to my medical records?

If you need to change providers you should arrange for copy or transfer of your medical records to your new provider, including the pathology report, reports of any surgeries, radiation or chemotherapy treatment, and the results of your most recent scans, x-rays, or other cancer evaluations.

I am in the process of diagnosis and staging for cancer. What should I do?

Patients should discuss with their oncologists what diagnostic and staging tests are likely to be most informative in developing an initial treatment plan and should prioritize in obtaining those tests if possible.

NCCS will provide answers to general questions about COVID-19 and patient advocacy on its website at canceradvocacy.org.

For more information and daily COVID-19 updates go to the cdc at <https://www.cdc.gov/>
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