NEWS FROM S•P•O•H•N•C

VOL. 27 NO. 8 SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC. MAY 2018

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

Tips for Traveling with a Feeding Tube

With Summer just around the corner, vacation plans are probably on your mind. These plans can be a bit more complicated if you are traveling with a feeding tube. With that in mind, a little preparation can go a long way when you're traveling far from home. The information shared here can be invaluable when it comes to travel – at any time. SPOHNC extends our best wishes to you for a wonderful adventure this summer – wherever you're off to! If you are flying, don't miss the information from the Transportation Security Administration in this article.

Consult Your Physician

Ask your physician whether travel is appropriate and what problems might be anticipated. Find out whether your doctor or an associate will be available by phone during your trip. (If possible get their pager or cell phone number, since the emergency may happen after hours.) In the event of a problem, you and the attending staff at the unfamiliar hospital will want to be able to reach a doctor who is familiar with you and your medical history. The physician's phone number, your medical history and other vital information should be carried with you at all times.

Ask your physician to write a letter explaining your need for the 'supplies' you are bringing with you — especially if you are traveling out of the country and/or with pain medications. (Note: for the purpose of this article, 'supplies' refers to everything you need for tube feeding, from tubing and syringes, to HEN formula, to medications and vitamins.) Pack a copy of the letter in each box of supplies and carry one on your person to share with customs and other travel officials. If possible have a copy of the letter written in the language of the country you are traveling to. For free foreign language translation help try: www.freetranslation.com or google translate.

Prepare for Emergencies

Have a plan of action in case of an emergency. Locate the nearest medical center or community hospital in the area you are traveling to. Ask your physician if he or she knows a physician familiar with tube feeding in the area you will be staying. The phone number of a local pharmacy is also helpful to find out ahead of time, in case you need a prescription phoned in.

Discuss with your physician what steps to take should you become ill or experience difficulties with your feeding tube. (Note: If you are traveling to the United States from another country, or traveling from state to state within the United States, the easiest way to replace prescription items is to visit a local on-call or urgent-care medical facility. State regulations require that a physician practicing in the state must write any prescription being filled in that state. Have contacting information for your local health care team with you; the ability to connect them with the physician in front of you will facilitate the writing of a prescription. A list of supplies, prescription items, etc., signed by your local medical team, can also expedite the process.

Research Your Supply Needs

Prepare a list of supplies well ahead of time. This will help you avoid overlooking any items. Pack a few extras in case of loss or damage. Talk to your physician/nurse about a back up plan (extra pump or battery, or how to gravity feed), in case you have trouble with your pump when you are on the road. If you are traveling abroad, you will likely need to plan ahead how you will overcome the issue of running your pump on an electrical system that is different from your home country's. One option is to use an adapter made expressly for your pump/battery charger for the country/region you are traveling to. Some pumps come with these - if not, you might be able to purchase one. Be careful about using a generic travel adapter/converter/transformer (that you might use for a hairdryer) with your pump/battery charger. You may 'fry' your battery charger when using one.

Another option is to run your pump on batteries (AA or 9V), which many pumps allow. Regular alkaline batteries typically last for one or two infusions, where lithium batteries may get you through more infusions. While you are still at home, run your infusion with batteries for a few days to test how long they last for your pump, and pack accordingly. You can also buy batteries in most countries, though for the small amount of weight and space, you may as well bring them from home.

TIPS FOR TRAVELING continued on page 2

Find SPOHNC on Facebook

News From SPOHNC is a publication of
Support for People with Oral and Head and Neck Cancer, Inc.

IN THIS ISSUE

TIPS FOR TRAVELING continued from page 1

A third option for getting around this issue, is to infuse by gravity which you would need to discuss with your physician before implementing.

Work with Your Home Care Company

If you work with a home care company to obtain your supplies, they may have an office or affiliate in the area you are traveling to that can deliver formula, and possibly supplies, directly to you at your destination. Many consumers have taken advantage of this opportunity. This avoids the fatigue of carrying the supplies yourself and reduces the worry about shipping delays. Just in case of a delay, it is advisable to pack at least one night's worth of supplies with you.

A second option is to have your home care provider ship your supplies for you. If your supplies will be shipped to a hotel, you'll need to explain to a hotel representative (likely the manager of the receiving or security department,) how to handle the supplies properly. It is best to do this when you make your reservation to ensure they can accommodate you, and then to verify the information a SECOND TIME the day you expect the supplies to arrive. Again, because of the possibility of delay, it is advisable to pack at least one night's worth of supplies with you.

To be sure your supplies are there when you need them, you may want to have them shipped such that they arrive a day ahead of you. This way you can verify before you leave home that they have arrived safely. (This may be helpful when going on a cruise.) Unfortunately, some companies will not ship supplies ahead for fear of mishandling or loss.

Having your supplies shipped overseas can be a more risky and time consuming adventure. If you decide to go this route, one experienced traveler suggests having them shipped 'directly' to you via air cargo. (He cautions against using an international courier such as Fed Ex or UPS, because no one with knowledge about the supplies will be there to answer questions if difficulties arise with customs officials.) He advises carrying at least three days worth of medical supplies or drugs you cannot replace with you in the cabin, choosing a direct flight whenever possible, and having the rest of the supplies arrive a day after you. This gives you time to orient yourself in the foreign city, and to be at the air cargo terminal when your supplies arrive so you can personally assure their safe and timely passage through customs.

No matter how you choose to ship your supplies, planning ahead and coordinating your efforts with your home care company can make this process a lot smoother and is well worth the extra effort. Before you leave, both you and the home care company should know details like how many boxes are being shipped, their contents (clearly labeled) and your travel itinerary (including flight/transportation information, destination addresses and phone numbers).

One consumer whose luggage was lost on a flight to Europe, recommends carrying on all of your supplies when traveling anywhere you cannot be guaranteed overnight delivery by your home care company. This approach can be very fatiguing, of course, and may incur a hefty financial charge for the extra baggage. Airlines should waive fees for medical supplies, so you should discuss this with the airline ahead of time, as the person at the baggage area may not be authorized to waive fees.

TIPS FOR TRAVELING continued on page 3

TIPS FOR TRAVELING continued from page 2

Another option for sending your supplies or other baggage that can tire you, is a door-to-door luggage shipping service. United Airlines offers this service, as do a few other shipping/courier-type companies. You'll want to research this option carefully, to be sure you've covered your risks.

Keep Solutions Cool

Refrigeration can be a nuisance, but there are some tried and true tips that experienced travelers follow. To reduce your load, pack items that require refrigeration separately, clearly labeling those that need to stay cold.

Unopened/unmixed HEN formula will require refrigeration only if it will be exposed to very warm temperatures, typically 77°F or higher (check the label on your can or package). Unused formula from an open can or packet that has already been mixed, should be refrigerated. Thus it is possible you will need refrigeration for your HEN formula only at your hotel, and not for the actual transporting.

To be sure your formula stays cool enough, use cooling packs on the bags/cans and cover both with ice. Don't forget to re-cool your cooling packs in a freezer whenever you have the opportunity — especially when traveling by car in hot weather.

If you need a refrigerator, when making a hotel reservation, be sure they can guarantee a refrigerator or your room, or space in their kitchen's refrigerator that you will have adequate access to. Note that small room refrigerators can cool items unevenly, so you may need to rotate your refrigerated items. When your hotel doesn't offer refrigeration, but does offer ice, try this method. Using plastic containers or Zip Lock baggies make some ice blocks, each morning, pour off any water that has melted and fill any empty space in the bag/container with ice cubes. These can last several days, depending on the weather. As the days pass, and your formula gets used, fill any empty space in the cooler with crumbled newspaper, and cover with a heavy bath towel.

Network with Other Travelers

Whether you are planning your first trip on tube feeding, or your first trip overseas, it's a good idea to talk to someone who has experience traveling with tube feeding. If you attend a SPOHNC Chapter support group, there may be someone in your group who has experience. If not, contact SPOHNC at 1-800-377-0928 and we will be glad to connect you with someone.

If you are flying on a US commercial airline, review security information/restrictions from the US Transportation Security Administration (TSA)

If you have any questions or issues with screenings, it is best to contact the TSA disability office at least 72 hours prior to travel.

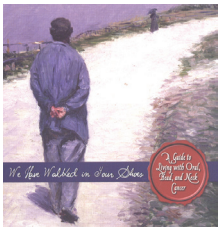
- E-mail **TSA.ODPO@TSA.DHS.GOV**.
- Call toll free at 1-855-787-2227 (Weekdays 8 a.m. – 11 p.m. EST, weekends and holidays 9 a.m. – 8 p.m. EST), or visit the TSA website at https://www.tsa.gov/travel/special-procedures.
- If you need to infuse during your flight, call ahead to make sure your pump is FAA approved. Some are not, and this small step will avoid a big issue.

- Lead TSA officers have two stripes on the shoulders of their uniform. These officers are able to provide immediate assistance and on-the-spot resolution to any passenger concerns at the checkpoint.

Editors Note: This article was reprinted with permission from The Oley Foundation. If you have any questions, comments or would like to find out more about the Oley Foundation, go to oley.org or contact the Oley Foundation at 518-262-5079.

"SPOHNC has been there every step of the way - assisting and educating throughout."
~ Gene M.

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



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

$14.95 includes shipping and handling.

Bulk order pricing
25+ books $13.50/book
50+ books $12.50/book including shipping & handling.

For bulk orders please call 1-800-377-0928 or email us at info@spohnc.org

Shopping Online for Gifts or Home Goods this Summer?

Remember to use

amazonsmile
You shop. Amazon gives.

Go to AmazonSmile, choose SPOHNC as your charity of choice and shop!

SPOHNC receives a portion of the proceeds from your purchase.

Happy Summer Shopping!!

"Like" SPOHNC on Facebook

CHAPTER NEWS

Words of wisdom, thanks and praise…

Our SPOHNC Chapter Facilitators are survivors, caregivers, healthcare professionals and friends. They are all special people, who give of themselves and their time, so generously and unselfishly. From time to time, we like to remind ourselves why we are so deeply indebted to them - for their passion in inspiring others. To finish up our calendar year of "News from SPOHNC", we thought it would be nice to share some of what comes to us by way of our dear friends and SPOHNC family - our SPOHNC Chapter Facilitators. Thank you for being who you are.

Contributed by Arkansas, Northwest SPOHNC Chapter Facilitators, Survivors, Jack and Temple Igleburger.

Last week, Temple unwrapped a chocolate candy and noticed a message on the inside of the wrapper that we thought would be something worthwhile for our survivors and everyone else in the world. The message from Layne B. in Ohio was;

"Inhale the future, exhale the past."

Even though you are being treated or now cured of cancer we must forget the pain and mental anguish and look to making the most of where you are today. We need to feel fortunate that the treatments, surgeries and recovery procedures were in place when we needed them.

There must be a reason why God has chosen us to walk in these shoes. It may not be just for us to say we survived. It could be to help someone close to us understand that you need to fight and persevere through life changing ordeals that we didn't choose.

We all have a day now and then that you just want to say; I'm tired of doing this, and just want to quit. We all need to fight; it is important to not give up and stay positive. The trick is to control these thoughts, straighten up, take one step at a time, continue to fight and look forward to welcoming tomorrow no matter what it brings you.

*A letter...*To Amy, Lewis and all of the SPOHNC Palm Coast Northeast, FL group,

Thank you so much for the beautiful surprise party for my retirement at your last meeting. I cannot express to all of you what you mean to me. I have such gratitude to walk into that room and see so many faces that I was privileged to journey with over time. Your experience with cancer taught me many things: patience, compassion, empathy, grace, sorrow and joy. I hold your experience in my heart on a professional level and a personal one. My brother is a 7 yr. survivor of head/neck cancer and recently also my best friend. Your journey helped me better understand their journey.

Cancer can be seen in a negative way in all of our lives and yet it brings gifts from the most unusual places. The gift of letting go. The gift of asking for help. The gift of finding comfort with others. The gift of humility. The gift of unknown strength and courage.

Thank all of you for sharing those gifts with me. And the constant reminder that you are not cancer, it can never take away who you really are.

All my love and best wishes,

Deborah

SPOHNC is Celebrating YOU!

As everyone gets ready for Summer, we have some birthdays that have already been celebrated and others that are coming in the Summer months. SPOHNC sends all good wishes for a wonderful year full of good health, prosperity and hope for the future!

Belated birthday wishes to JR Newton (April 30th) of SPOHNC Terre Haute, IN and Bob MacMillan (May 5th) and Frank Marcovitz (May 15th), of SPOHNC Syosset, NY.

And an early Happy Birthday to Sandy Pence (July 31st) of SPOHNC Terre Haute, IN.

All the Best to Each of You!!

THIS SUMMER
We hope to hear from you!

Send us your birthdays, good news, sharing stories and chapter news.

Send to info@spohnc.org

HEAD AND NECK CANCER NEWS

Protect Every Child from HPV Cancer

We live during a time where we can greatly reduce the number of people who are diagnosed with HPV (human papilloma virus) positive tumors. The most common HPV positive tumors are diagnosed in cervical cancer and tumors that grow in the mouth and back of the throat. The HPV vaccination series can protect future generations from developing these cancers. It seems so simple. Unfortunately, many disparities and misinformation challenge the goal of attempting to vaccinate most of our pre-teen population.

HPV and Cancer

The HPV virus is a large group of related viruses. It is a common virus that most people will be exposed to during their lifetime. Each virus in the group is given a number, which is referred to as the HPV type. Some types of HPV can cause warts (papillomas). These are considered low-risk viruses and rarely cause cancer.

More concerning are high-risk HPV types because they can cause cancer in both men and women. The high risk virus can generate cell changes which lead to pre-cancerous lesions and are more likely to grow into cancer over time. Drs. Misiukiewicz and colleagues reported in the October, 2017 *News from SPOHNC*, anti HPV antibodies can be present in the blood for more than 10 years before the diagnosis of oropharyngeal squamous cell carcinoma. Common high-risk HPV types include HPV 16 and 18.

HPV Vaccination is Cancer Prevention

The FDA (Federal Drug Administration) approved the first HPV vaccination in 2006. The vaccination is most effective when administered before exposure to the virus, as in measles and pneumonia. Males and females should be vaccinated against HPV at age 11 or 12. Recommendations state that the series is completed by age 13. It is important to understand that young people can still benefit for the vaccination series even if they don't meet the recommended guidelines.

The HPV vaccine is given as a series of two shots 6 to 12 months apart. More than 270 million have been distributed around the world in the past 10 years and there have been no serious safety concerns.

"Mission: HPV Cancer Free"

"Mission: HPV Cancer-Free" is the American Cancer Society's (ACS) new campaign to partner with volunteers, parents, community leaders, health care providers and organizations to increase the HPV vaccination rates for preteens. The goal is that by the 20 year Anniversary of the FDA approval of the vaccination series, at least 80% of preteens have received the vaccination series.

TheACS campaign will launch in the first week of June. The campaign has 2 goals: *Increase HPV vaccination rates for preteens Eliminate gender and geographic disparities in HPV vaccination rates*.

Unfortunately, this vaccination series has encountered reluctance amongst health care providers and parents. It will take education to go beyond the misconception that the vaccination series is giving children permission to engage in sexual behaviors. The hope is to normalize the vaccination series and prevent cancer.

Consider Becoming a Volunteer Champion

The HPV vaccine delivers on a dream many have held for decades: a cancer prevention vaccine. Together we can help prevent six different cancers, including oral and throat cancer. Survivors, loved ones of survivors, health care professionals, and folks who want to wipe out HPV related cancers are asked to consider getting involved. There are many opportunities available. It may be speaking at a community event or parent groups, writing an article for a work newsletter, etc. If interested, please contact acs.hpv.vacs@cancer.org.

Editors Note: This article was contributed to SPOHNC by Mary Ellyn Witt, RN, MS, AOCN® Oncology Nurse – Survivorship Care University of Chicago Comprehensive Cancer Center at Silver Cross New Lenox, Illinois & Marcie Fisher-Borne, PhD HPV Vaccination – Director American Cancer Society Raleigh, North Carolina

HEAD AND NECK CANCER NEWS

Celecoxib May Help Curb Opioid Use After Head and Neck Cancer Surgery

April 30, 2018 - NEW YORK (Reuters Health) - Celecoxib is associated with lower perioperative opioid requirements after head and neck surgery with free tissue reconstruction, researchers say. Dr. Richard Cannon of the University of Utah School of Medicine in Salt Lake City matched 51 patients who received celecoxib postoperatively with 51 who did not. The mean age was 61.6 in the celecoxib cohort and 66.1 for controls. Half of both groups were women.

Celecoxib, 200 mg, was given twice daily through a feeding tube for at least five days starting on postoperative day one. Oral opioids - hydrocodone, oxycodone, morphine, and hydromorphone - were offered on a schedule and as needed, with doses converted into morphine milligram equivalents (MMEs). IV opioids were used for severe pain.

As reported online April 18 in JAMA Otolaryngology-Head and Neck Surgery and at the American Head & Neck Society annual meeting in National Harbor, Maryland, treatment with celecoxib was associated with decreased use of oral opioids (mean difference in daily MMES, 9.9 mg), IV opioids (mean difference, 3.9 mg), and total opioids (mean difference, 14mg).

Among patients who underwent the most common ablative procedure - composite oral resection - the effect was more significant. In this subset, the mean MMEs per day with vs without celecoxib, respectively, were 26.0 mg vs. 51.1 mg for oral drugs, 0.9 mg vs. 4.4 mg for IV administration, and 26.9 mg vs. 55.5 mg overall. There was no significant difference in complication rates between the two groups.

"Rofecoxib, another COX-2 inhibitor, was taken off the market in 2004 owing to concerns about increased cardiovascular risk," Dr. Cannon noted in an email to Reuters Health. "However, this concern has not been shown with celecoxib after long-term multi-institutional randomized clinical trials on numerous patients . . . demonstrated no difference in incidence of cardiovascular adverse events."

"We saw no clinical difference in cardiovascular events in the cohort of patients that received celecoxib versus those patients that did not received celecoxib," he added.

"Our data has limitations but represents a pilot study to evaluate potential mechanisms to decrease opioid use in patients who undergo head and neck surgery," he said.

"Future studies should include prospective placebo-controlled trials including patient pain scores and patient-centered outcome measurements. Trials like this will be essential in providing further insight into the qualitative pain levels while minimizing potential observer bias," he concluded.

Dr. Christopher G. Gharibo, associate professor of Anesthesiology, Perioperative Care, and Pain Medicine and Orthopedic Surgery at NYU Langone Health in New York City, agrees that "celecoxib can improve the quality of the pain relief while reducing the reliance on opioids and decreasing discharge doses."

However, "celecoxib and other NSAIDs may be associated with exacerbation of end-organ diseases (including) cardiovascular, renal and gastrointestinal," he told Reuters Health by email.

While NSAIDs other than celecoxib might be similarly effective in reducing opioid requirements, he said, "They're associated with platelet inhibition and increasing the bleeding risk."

###

HEAD AND NECK CANCER NEWS

Skipping the SICU Post Head and Neck Cancer Surgery May Improve Outcomes

May 19, 2018 - *In this study, a specialized nursing care unit was incorporated into SO, allowing direct transition from PACU and bypassing the SICU.*

WASHINGTON, DC — Bypassing the surgical intensive care unit (SICU) and reducing the length of stay may improve outcomes for patients with head and neck cancer (HNC) after surgery, a study presented at the 2018 Oncology Nursing Society (ONS) Annual Congress has shown.

Although HNC surgery is a major procedure, many patients are admitted to SICU directly from the post-anesthesia care unit (PACU) for 24 to 48 hours as they require frequent monitoring of vital signs and flap perfusion before being transferred to the surgical oncology unit (SO), prolonging the length of stay. "The postoperative care for these patients can be very labor intensive since the monitoring is hourly," said Cara Henderson, RN, BSN, CMSRN, a patient service manager in surgical oncology. "We needed to look at a way how we can accomplish this in the inpatient setting with surgical oncology."

For this study, a specialized nursing care unit was incorporated into SO, allowing direct transition from PACU and bypassing the SICU. An interdisciplinary team worked to select appropriate candidates for the study, and the surgeons educated the unit staff on the surgical procedure and postoperative care.

After 2 years, results showed that not only was hospital stay shortened by 3 days (10 days vs 7 days), only 6% of patients were sent to the SICU from the PACU (100% pre-implementation), and the rate of readmission decreased from 16% to 3%.

###

"Faith is the bird that feels the light when the dawn is still dark."

—Poet Rabindranath Tagore

photo credit: PJ Jordan, Caregiver & NSVN Volunteer

Share SPOHNC on Facebook

photo credit: PJ Jordan, Caregiver and NSVN Volunteer

Cool Summer Fun from "Eat Well Stay Nourished A Recipe and Resource Guide For Coping With Eating Challenges"

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

Hawaiian Float *(from Volume 2)*

2 Tbsp. orange-pineapple juice concentrate (undiluted)
1 pkg. or ¼ c. vanilla instant breakfast powder (or Slimfast powder)
½ c. ice
½ c. evaporated whole milk
¼ c. lime sherbet

Mix all ingredients in a blender. Blend until smooth. Store any remaining in the refrigerator. Serves 1. *427 calories/serving.*

~ Maria V., New York

Key Lime Pie *(from Volume 1)*

1 graham cracker pie crust
1 (4 serving size) Pkg. sugar free lime flavor gelatin
¼ c. boiling water
2 (6 oz) Key lime pie flavor light yogurt
1 (8 oz) fat free Cool Whip, thawed

Dissolve gelatin in boiling water. Cool. Stir in yogurt with a wire whisk. Fold in Cool Whip with a wooden spoon. Spread into crust. Refrigerate at least 2 hours.
Note: Any flavor gelatin and yogurt works – strawberry, peach, cherry etc. Serves 8.
224 calories per serving.

~ Sister Mary Ryan, Indiana

Visit the SPOHNC website at www.spohnc.org

TIME FOR SHARING...

Jamesport man, a retired FDNY firefighter, battles 9/11-related cancer

Two years before Mr. Brickman's initial cancer diagnosis, President Obama signed the James L. Zadroga 9/11 Health & Compensation Act, which was named after a New York City Police Department officer who died of a respiratory disease related to his efforts after 9/11. The fund was designed to help the growing number of first responders who were succumbing to various diseases in the years following the terrorist attack.

The Zadroga Act was first written to cover 9/11-related health problems only through 2015. When efforts stalled in Congress to extend the health care program, it took a long, consistent effort by the families of those affected to get the government to act. Jon Stewart, former host of "The Daily Show," was a strong advocate for first responders and produced a powerful segment last December in which he attempted to reinterview first responders he had originally met 5 1/2 years earlier. Only one of the four men could return. One had died and the other two were too sick to return.

Later that month, the House and Senate both voted to extend the Zadroga Act for 75 years, guaranteeing that men like Mr. Brickman will continue to receive the coverage they need. "Isn't that what this country is about?" Mr. Brickman said. "You take care of your own."

Mr. Brickman, who said first responders weren't provided adequate protection from the toxic air at ground zero, tries to avoid getting swept up in the politics. He knows there have been some local politicians who fought hard for the first responders. And he knows that without the support of the health coverage, he could never afford medications like one drug, used as part of a study, that cost about $13,000 a month."It just seems unfair that they would stretch this out and give people like me anxiety," he said.

Mr. Brickman rarely talks about his experiences on 9/11 or attends support groups, although he recently visited Fighting Chance in Sag Harbor, a group for cancer survivors. He shies away from attending local 9/11 memorial ceremonies as an honored guest and he has never visited the ground zero memorial. On a recent visit he wore a shirt with the Superman logo on it and Superman-themed shoes. His kids, Steven, 13, and Quinn, 10, like to think of their dad as a superhero after everything he's been through. He sits on the porch of his Jamesport cottage beneath a large banner of a U.S. flag designed with the names of all the 9/11 victims.

He has a large framed copy of a 2001 issue of The New York Times that features the photographs of every firefighter who died on 9/11, such as Lt. Robert Nagel, with whom Mr. Brickman worked closely at Engine 58. He doesn't display the frame; his house is too small, he said. But he occasionally takes it out to show his boys and share stories about the firefighters he knew. His son Steven's middle name is Robert after Mr. Nagel.

Steven Jr. was born two years after 9/11. Mr. Brickman said his son helped provide him with a renewed sense of life after the depression that came with leaving his job before he was prepared to and the devastation of 9/11. The former fireman became a stay-at-home dad while his wife worked as a waitress."He was in charge of everything," Ms. Brickman said. "He was always very hands-on with the kids."

Ms. Brickman typically stayed behind with the kids when her husband traveled into the city for doctor appointments. He relied on the steady support of friends and family, such as Fran Trapani, a retired fireman in a neighboring firehouse, his brother Gerard, who's also a fireman, and a lifelong friend, Chief John Sudnik. Mr. Brickman and Mr. Trapani became close friends. Mr. Trapani's mother had died at Sloan Kettering and two of his brothers have undergone cancer treatment.Mr. Trapani, who lives in Farmingville, was familiar with the facilities in the hospital and agreed to help guide his friend.

"He was there for every single visit," Mr. Brickman said. "He's a great guy. I don't know how I would have done it without him."

As Mr. Brickman looks back now, 15 years after 9/11, there are no heroic stories of how he helped pull someone from the rubble. Hope quickly faded at ground zero of finding anyone alive after a few days. The destruction was simply so catastrophic that even finding bodies intact was rare. He remembers the blank, empty stares on the faces of firefighters; the small fires that burned untouched around ground zero as people dug through debris; the late summer heat; the smell of death that set in as time passed."It was the kind of s— that made me cry when I called my wife," he said.

It would be understandable for Mr. Brickman to wish he had never left his home that September. He had no professional duty to be there. They never did pull anyone to safety. And he's now stricken with diseases that could end his life.But he doesn't look at it that way.

No regrets, he said. He still dreams about putting on the uniform."If I could fight one more fire I'd be thrilled," he said.

Editors Note: This story was reprinted with permission from the Suffolk Times, in Suffolk County, New York. To contact Steve Brickman email verygrateful111@gmail.com

Inspire Someone Today

SPOHNC is seeking your story, to share with those who are just beginning their cancer journey.

To find out how you can help a newly diagnosed patient, contact Chris at SPOHNC at 1-800-377-0928, x4 or email c.leonardis@spohnc.org.

HEAD AND NECK CANCER NEWS

Compound in citrus oil could reduce dry mouth in head, neck cancer patients

May 21, 2018 - A compound found in citrus oils could help alleviate dry mouth caused by radiation therapy in head and neck cancer patients, according to a new study by researchers at the Stanford University School of Medicine.

The compound, called d-limonene, protected cells that produce saliva in mice exposed to radiation therapy -- without diminishing the tumor-fighting effects of the radiation. The researchers, led by graduate student Julie Saiki, also showed that d-limonene taken orally is transported to the salivary gland in humans. The study was published online May 21 in the *Proceedings of the National Academy of Sciences*.

The finding was possible because of a close collaboration between clinicians and basic scientists, said co-senior author Daria Mochly-Rosen, PhD, professor of chemical and systems biology. "This is a perfect example of two pieces that could not work alone." "Stanford is a fertile ground for collaboration," added Quynh-Thu Le, co-senior author and professor and chair of radiation oncology.

About 40 percent of head and neck cancer patients who receive radiation therapy develop dry mouth, known clinically as xerostomia. It's more than uncomfortable: patients struggle to speak and swallow and are more likely to develop oral pain or dental cavities, and the condition can lead to tooth removal in some cases, Le said. And, although some recovery can occur in the first years after the therapy, once saliva production is impaired, it is usually gone for life.

Radiation can kill salivary cells

One drug, called amifostine, is approved for use during radiation therapy to try to ward off dry mouth, but its side effects, including nausea and potential low blood pressure, are common, so it is rarely used in the clinic, Le said.

Many of the saliva-producing cells that are needed to keep the mouth constantly moist are found in a pair of structures called the submandibular glands, tucked under the lower jawbone on each side of the chin. Radiation often kills these cells and, more troublingly, also salivary stem and progenitor cells, those juvenile members of the population that are needed to rebuild and restore the capacity to make saliva.

The key to retaining salivary function is protecting these rare but critical stem and progenitor cells. That's tricky because, following radiation therapy, toxic, highly reactive compounds called aldehydes are created in the gland, gumming up cellular function.

Le, the Katharine Dexter McCormick and Stanley McCormick Memorial Professor, who specializes in treating head and neck cancer, said she had spent a decade hearing from her patients about their struggles with dry mouth. "I wanted to do something," she said.

Her initial strategy was to try to regenerate salivary stem cells and, while working with these cells, her lab found that they contain high levels of an enzyme called aldehyde dehydrogenase 3A1, or ALDH3A1. The enzyme is a member of the large aldehyde dehydrogenase family of enzymes, proteins that initiate or speed up chemical reactions, that can defang troublesome aldehydes. But ALDH3A1 isn't a match for the radiation-unleashed aldehydes on its own. She needed to find something to amp it up.

Looking to the East

Le had met with Mochly-Rosen through SPARK, a program founded and co-directed by Mochly-Rosen, that shepherds basic science discoveries into the clinic. Mochly-Rosen, who is the George D. Smith Professor in Translational Medicine, had been working on aldehyde dehydrogenases for more than a decade and had obtained access to a library of 135 traditional Chinese medicine extracts.

Many of those extracts have been used as treatments for various ailments in humans for hundreds of years, boosting the likelihood they are safe to use, Mochly-Rosen said.

Her team found that seven of these 135 extracts boosted ALDH3A1 activity. It was up to Saiki to see if she could break apart these complex natural extracts -- from plants including tangerine, lotus and an Asian rhizome known as zhi mu in Chinese -- to find out what, exactly, was activating the enzyme.

"She did the unthinkable, a really amazing achievement. She found the single active ingredient that activates the enzyme, ALDH3A1," Mochly-Rosen said.

Admittedly, Mochly-Rosen and Saiki said, a bit of luck and a fair amount of trial-and-error were involved. D-limonene stood out from other compounds in the extracts because it is broken down relatively quickly in the body and has been deemed by the Food and Drug Administration as a food flavor "generally recognized as safe" that has been approved for use as a food additive, Saiki said.

Saiki said she was pleasantly surprised by her finding. "It's a very common molecule, and sometimes as a scientist you wonder, Why hasn't anyone seen this before?" she said. Next, they had to see if d-limonene would rev up ALDH3A1 in living cells.

Testing in mice, and humans

A series of experiments with mouse cells that had been exposed to radiation showed that d-limonene reduced aldehyde concentrations in both adult and salivary stem and progenitor cells. Even when the cells were treated weeks after radiation exposure, d-limonene still improved their ability to recover, repair gland structure and produce saliva. Mice that ate d-limonene and were exposed to radiation also produced more saliva than mice that did not receive d-limonene and were exposed to radiation. The researchers also learned that d-limonene wasn't likely to boost saliva production so high that mice, or humans, would be drooling -- the compound didn't increase saliva production in mice that hadn't been exposed to radiation. And they confirmed that d-limonene did not affect tumor growth or interfere with the tumor-shrinking effects of the radiation in mice.

A further set of experiments pulled back the curtain on d-limonene's work: it was stopping the expression of messages that trigger the salivary stem and progenitor cells to self-destruct.

Buoyed by these positive results, the researchers wanted to know if the compound had any hope of helping patients. To work, it would have to be active inside the salivary glands. To find out, they launched a phase-0

continued on page 10

Connect with SPOHNC's "group" on Facebook

continued from page 9

study, an early clinical trial in a small number of patients to see if d-limonene, taken by mouth in a capsule, would be distributed to the salivary gland. Four participants who were having a salivary gland tumor removed took d-limonene for two weeks before the surgery. When the tissue was examined after it was removed, researchers found high levels of d-limonene, showing that it has the potential to be used therapeutically in humans -- it reaches the salivary gland tissue.

The patients did experience one quirky side effect: Citrus-infused burps.

Next, the team plans to start the clinical trial process, which will take several years and require a multi-institutional collaboration, Le said. "If it works, then this type of drug would be used safely to prevent dry mouth in patients in the long run and make it much easier for patients to tolerate the radiation treatment with an improved quality of life after the treatment," she said.

What's New?

SPOHNC Gets a Makeover!

Once in a while, it feels good to get a makeover, make a change and do something different. Even organizations like SPOHNC can feel that way. That's why SPOHNC is in the midst of a makeover.

Even while we help you find someone to connect with, or a support group to attend, or while we help you find the resources you need – a ride to treatment, funding to help get you there, help with your mortgage or rent, your bills, prescriptions and other expenses, we have been working hard behind the scenes.

SPOHNC is dedicated to raising awareness and meeting the needs of oral and head and neck cancer patients through its resources and publications. The pace of the world, technology and medicine has become so swift and ever changing, so we made it our business to provide you with a more user friendly and more mobile accessible website. We're excited to announce that we have been keeping a secret from you – our new look! Coming soon, our updated website will be here to help you. Look for a formal anouncement. We've been working hard to bring you the best way to find information, resources and hope…because

"Together We Heal"

HEAD AND NECK CANCER NEWS

Monitoring tool lowers symptom severity for head, neck cancer

May 17, 2018 - Patients with head and neck cancer who underwent remote monitoring by a mobile app and sensor technology had less severe symptoms than patients who had weekly doctor visits, according to a study scheduled for presentation at the ASCO Annual Meeting.

Both cancer and treatment-related symptoms appeared less severe among the technology-monitored group. Clinicians detected concerning symptoms early and responded to them more.

"Head and neck cancer patients who receive radiation treatment have a high symptom burden and are also at increased risk for dehydration during treatment," Susan K. Peterson, PhD, professor in the department of behavioral science at The University of Texas MD Anderson Cancer Center, said during a press conference. "Previously, we showed that it was feasible to use mobile and sensor technology to identify treatment-related symptoms and early dehydration in patients while receiving their radiation treatment as part of their outpatient care."

Peterson and colleagues studied 357 patients (mean age, 60 years; 21% women; 85% white) receiving radiation for head and neck cancer.

Researchers randomly assigned patients to usual care (n =188) or to a technology system called CYCORE (n = 169) — developed by four institutions with a grant from the NCI — which included Bluetooth-enabled blood pressure cuffs and weights scales, as well as a mobile tablet with a symptom tracking app. The CYCORE technology transmitted symptom data back to the patient's physician.

"Patients' ages ranged up to 86 years, which supports the notion that the use of technology-based intervention can be feasible in older patients," Peterson said. "Also, we had good adherence to the CYCORE regimen."

More than 80% of patients adhered to daily monitoring. All patients had weekly in-person doctor visits.

Patients completed the MD Anderson Symptom Inventory at baseline, at the end of their radiation therapy, and 6 to 8 weeks following the completion of radiation therapy. Patients scored their symptoms on a scale of 0 to 10, where 0 indicated no symptom or pain and 10 indicated the highest level of symptom severity. Baseline symptom severity score did not differ between the two groups.

At the completion of radiation therapy, patients monitored with CYCORE had lower mean scores for general symptoms (2.9 vs. 3.4; P = .003) and head and neck cancer-related symptoms (4.2 vs. 4.8; P = .009) than those who received usual care.

The technology-monitored group also had better symptom scores at 6 to 8 weeks after radiation therapy (general, 1.69 vs. 1.96; P = .003; cancer specific, 1.78 vs. 2.11; P = .009).

"Good patient adherence — plus the fact that this posed a minimal burden on clinicians to do the monitoring — supports the use of symptoms like CYCORE during intensive treatment periods in cancer care," Peterson said. "Using sensor and mobile technology to monitor patients during critical periods of outpatient treatment can provide a timely source of information for clinical decision-making and may improve quality of life and health outcomes."

The next steps include working to implement these technologies into cancer care, including in community centers, where most patients receive their care, according to Peterson.

###

CHAPTERS OF SPOHNC
(125+ and growing!)

Contact SPOHNC at 1-800-377-0928 for Chapter information & Facilitator contact information

ALABAMA
BIRMINGHAM, HUNTSVILLE, MOBILE

ARIZONA
CHANDLER, MESA/GILBERT,
PHOENIX (2), SCOTTSDALE

ARKANSAS
FAYETTEVILLE

CALIFORNIA
BERKLEY,
NEWPORT BEACH,
ORANGE-UCI,
SAN DIEGO, SOUTH SAN FRANCISCO,
SANTA MARIA, STANFORD, VENTURA

COLORADO
COLORADO SPRINGS,
DENVER

DC
GEORGETOWN

FLORIDA
DEERFIELD BEACH, FT MYERS,
JACKSONVILLE (2), NAPLES,
PALM COAST/NORTHEAST,
WINTER PARK

GEORGIA
ATLANTA,
SAVANNAH

IDAHO
MOSCOW

ILLINOIS
EVANSTON,
MAYWOOD, MORRIS, SPRINGFIELD

INDIANA
AVON
SOUTH BEND, TERRE HAUTE,

IOWA
DES MOINES

KANSAS
KANSAS CITY

LOUISIANA
BATON ROUGE, NEW ORLEANS

MARYLAND
BALTIMORE-GBMC, BALTIMORE-JHMI,
LIBERTYTOWN

MASSACHUSETTS
BOSTON, CAPE COD,
DANVERS

MICHIGAN
ANN ARBOR,
SAGINAW, WARREN

MINNESOTA
MINNEAPOLIS, ST. PAUL

MISSOURI
ST. LOUIS/DPCC

MONTANA
BOZEMAN

NEBRASKA
LINCOLN, OMAHA/MCC

NEW JERSEY
CAMDEN, ENGLEWOOD,
LONG BRANCH, PRINCETON/UMC,
TOMS RIVER

NEW YORK
BUFFALO, MANHATTAN/BI,
MANHATTAN/MS, MANHATTAN/NYU,
MIDDLETOWN, NEW HYDE PARK,
ROCHESTER, STONY BROOK, SYOSSET,
WHITE PLAINS

NORTH CAROLINA
DURHAM

OHIO
CINCINNATI, CLEVELAND,
DAYTON

OREGON
MEDFORD

PENNSYLVANIA
DUNMORE,
HERSHEY, LANCASTER,
PHILADELPHIA, YORK

SOUTH CAROLINA
GREENVILLE (UPSTATE)

TENNESSEE
NASHVILLE

TEXAS
AUSTIN, DALLAS,
FORT WORTH, IRVING (2),
SAN ANTONIO

VIRGINIA
CHARLOTTESVILLE, FAIRFAX,
NORFOLK, RICHMOND

WASHINGTON
KIRKLAND

WISCONSIN
APPLETON

"We are grateful that you are there..."
~Lewis & Amy B.
SPOHNC Palm Coast NE, FL Chapter Facilitators

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER (SPOHNC)

MEMBERSHIP APPLICATION
SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER, INC.
P.O. Box 53, Locust Valley, NY 11560
Membership includes subscription to eight issues of *News From SPOHNC*

Name_____Phone (_____)_____

Address_____Email Address_____

Address_____

City_____State_____Zip_____

Please Check: Survivor ____Friend ____Health Professional (Specialty) _____

First time member_____ Returning member_____

ANNUAL MEMBERSHIP
❑ $30.00
❑ $35.00 Foreign (US Currency)
Including free Product Directory

CONTRIBUTIONS
❑ Booster, $35+ ❑ Donor, $50+ ❑ Sponsor, $100+
❑ Patron, $500+ ❑ Benefactor, $1,000+ ❑ Founder, $5,000+
❑ Leaders Circle, $10,000+ ❑ Visionary Circle $15,000+

Call 1-800-377-0928
to become a member and make a contribution by credit card or order online at www.spohnc.org

Best wishes from SPOHNC for a Super Special Summer.

SPOHNC is open for business, however we do take a hiatus during the summer months.

Call us if you need us at 1-800-377-0928 or email us at info@spohnc.org. We're here for you!

See you in September!

SUPPORT FOR PEOPLE WITH
ORAL AND HEAD AND NECK CANCER
P. O. BOX 53
LOCUST VALLEY, NY 11560-0053

ADDRESS SERVICE REQUESTED

NON-PROFIT
ORGANIZATION
U.S. POSTAGE
PAID
LOCUST VALLEY, NY
PERMIT NO. 28