

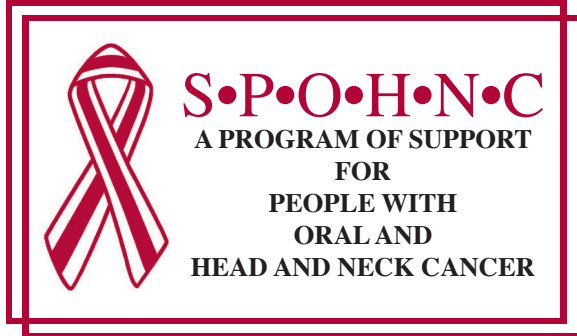
# NEWS FROM S·P·O·H·N·C



VOL. 26 NO. 8

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

MAY 2017



## Disability Benefits for Oral Cancers and Cancers of the Head and Neck

After the initial shock of the diagnosis wears off, it's time to start thinking of how you and your family will get by financially while you battle cancer. Your illness and the treatments necessary to combat it will put you out of work for months or maybe even permanently. Worrying about the bills is the last thing you should be doing during this time. Disability benefits from the Social Security Administration (SSA) help ease the financial burden and allow you to focus your energies elsewhere, namely, on fighting cancer and on spending quality time with those you love.

### Cancers That Automatically Qualify Medically for Benefits

There are dozens of cancer disability listings that appear in the SSA's Blue Book. Any applicant that meets or matches one of these listings is automatically eligible for disability, at least from a medical perspective.

Oral and other head and neck cancers that appear in the Blue Book include, among others, those that affect:

- the soft tissues of the neck, which includes tissues that are not bone, glands, the esophagus or larynx.
  - thyroid, salivary glands, and the bones of the head and jaw.
- Qualification requirements can vary significantly from one listing to the next, but generally, cancers must be advanced or difficult to treat in order for them to qualify automatically for benefits.

Here are just two examples:

- Salivary gland cancer qualifies for benefits only if it has spread or metastasized beyond the regional lymph nodes.
- Cancer that affect the bones of the skull or jaw only qualifies if it has spread to distant lymph nodes or invaded the sinuses.

In other words, in most case, a diagnosis of cancer is not enough to

qualify. Instead, the SSA must see through your medical records that beating your cancer will take a lengthy battle or that your cancer is so advanced or aggressive that the battle is ultimately unwinnable.

Although some of the listings for cancers of the head and neck strictly limit the ways in which you can qualify, others afford multiple qualification criteria. For example, soft tissue cancers of the head and neck qualify for benefits when they are:

- Metastatic, having spread to distant lymph nodes.
- Inoperable or cannot be effectively treated through surgery.
- Of a particularly aggressive form, like small or oat-cell carcinoma.
- Treated using more than one type of treatment approach, such as chemotherapy and radiation therapy.
- Additionally, if your cancer is treated through a multimodal approach, you qualify for benefits for 18 months from the date of diagnosis. After the expiration of that period, you may continue to qualify for benefits even once that first 18 months is up, though the SSA must review your claim again for continued eligibility. This time, they'll look at your eligibility from the perspective of any residual effects your treatments have left you with. If there are severe impairments that still prevent employment, even if your cancer was successfully treated or cured, you may still be able to get disability.

### Meeting the SSA's Technical Eligibility Requirements

Medically qualifying for benefits is only part of the eligibility review the SSA conducts. You must also meet the technical eligibility rules:

- **Social Security Disability Insurance (SSDI)** benefits are intended for disabled workers and therefore require you have a work history during which you paid into the Social Security system through employment taxes.
- **Supplemental Security Income (SSI)** benefits are designed to support the most financially needy among the disabled population and therefore require you have very limited income and other financial resources for supporting yourself.

Although the SSA's rules are strict, many people are able to receive benefits because of provisions within the program regulations. For example, to meet the criteria for SSDI, you must prove that you have the required work credits needed to qualify. These work credits are based on your contributions to Social Security from your payroll taxes. The amount required is not the same for everyone. The work credit requirement is based on your age at the time you become disabled. Typically, between 20 and 40 work credits are necessary to qualify, and credits usually accumulate at the rate of about four per year of employment.

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**Qualifying for Benefits Without Meeting a Disability Listing**  
 Many cancers can qualify for benefits, even when they don't meet the SSA's Blue Book-listed severity levels. For example, if it's caught early and successfully treated, cancer of the salivary glands won't be approved through the Blue Book. It may however still qualify for benefits, if the disease and treatments required to beat it have left you with lasting or permanent residual impairments. These impairments can include limitations on the ability to go about daily activities, such as work, socializing, and self-maintenance.

To be approved outside of the Blue Book, the SSA must review your "residual functional capacity" or RFC. Provided your medical records and other documentation show you have severe physical and/or mental limitations that prevent employment, you may still receive a disability approval. With this in mind, work closely with your doctor to document the residual effects of your cancer and cancer treatments, in case an RFC review is necessary for approval.

**Compassionate Allowances**

The most advanced and untreatable cases of head, neck, and oral cancers qualify for expedited review and approval under the SSA's Compassionate Allowances (CAL) program. The Compassionate Allowances program is a program for those with severe conditions that would require expedited processing of their claims. This ensures applications are reviewed as quickly as possible, in an effort to get benefits to those who need them most.

**Preparing to Apply for Disability**

Before applying for benefits, you'll want to discuss with your doctor your plans to submit an application. He or she can review the disability listings in the Blue Book and the SSA's evidence requirements. If your medical records are lacking in documentation, your physician can help your disability approval chances by ordering additional tests or by fully documenting the residual effects of your treatments, including the limitations you've been left with after undergoing anti-cancer therapy.

Also prior to beginning your application, you'll want to consider reviewing the SSA's Disability Starter Kit. In this kit, you'll find detailed information about what types of information you'll need to apply for benefits, important information about the application process, and a worksheet to help you prepare for an interview with an SSA representative.

**Submitting Your Application for Benefits**

When you're ready to apply for benefits, keep in mind that the SSDI and SSI programs require separate applications:

- The SSDI application can be completed online or at the local office, with the help of an SSA representative.
- The SSI application however requires a personal interview with an SSA representative.

SSI interviews are often done at the local office. The SSA can also use the information from the online SSDI application to commence a claim for SSI and then follow up with you to complete the necessary interview.

**Appealing a Denial**

If you've been denied benefits after your initial application, you can appeal the SSA's decision. This process has multiple stages

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of appeals, so being denied again after one stage doesn't mean that you are entirely unable to receive benefits. The appeals process includes these steps:

- **Request for Reconsideration:** After an initial denial, you can have your application reviewed by a different claims examiner. For this step, you have 60 days from the time you've been notified of your denial to file an appeal. There are exceptions to this time limit for "good cause", such as being hospitalized. You can include new information about your claim (such as new medical records) with your reconsideration form (Form SSA-561). This option is available in most, but not all states and Social Security regions. You may want to ask your local SSA office if this is available for you at the time of your initial application.
- **Appeal Hearing:** If you are again denied benefits after a request for reconsideration, or are in a state or region that does not accept requests for reconsideration, you can request a hearing with an Administrative Law Judge (ALJ) within 60 days of your reconsideration denial. While this may not take place in a courtroom, it is still a legal proceeding. You can apply for a hearing online, or by submitting Form HA-501.
- **Appeals Council & Remands:** You can file an appeal of the ALJ's decision within 60 days by submitting Form HA-520. The Appeals Council does not make a determination based on your evidence and application, rather they review the case for legal or procedural errors made by the ALJ. When the Appeals council reviews a case, they can either:
  - Reach a new decision and award benefits,
  - Return the case to the ALJ to reconsider, or
  - Issue a denial
- **Federal District Court Appeal:** This is the final stage of the appeals process. If the Appeals Council issued a denial, then you have another 60

days to file a Federal District Court appeal. In this case, you would need to pay a filing fee, or if that presents a significant hardship, it may be waived after making a request for a waiver in writing. In most cases, this stage would require legal assistance from an attorney.

If you've been denied, it may be a good idea to contact an attorney or disability advocate as they can help you through these stages. If you plan on appealing the SSA's decision, do not submit a new application for benefits, as this can affect things like any back pay you may be entitled to, or eligibility for benefits.

*Editors Note: This article was written by the Outreach Team at Disability Benefits Help. They provide information about disability benefits and the application process. To learn more, please visit their website at [www.disabilitybenefitscenter.org](http://www.disabilitybenefitscenter.org) or by contacting them at [help@ssd-help.org](mailto:help@ssd-help.org).*



## CHAPTER NEWS

### Happy Anniversary SPOHNC Palm Coast, Northeast, Florida

June celebrates the beginning of Summer, but this year it also celebrates a milestone for a very special SPOHNC Chapter. Congratulations to SPOHNC's Palm Coast, Northeast Florida Chapter on their anniversary – 5 years of support!

When Sandi Walker contacted SPOHNC in 2011 to order a cookbook for Amy and Lewis Beilman, little did anyone know what was to come the following year. After Lewis finished treatment, he and Amy contacted SPOHNC to find out how to start up a Chapter, and the SPOHNC Palm Coast Northeast Chapter was born. The Beilman's found the formula that works for their meetings, and their group has grown steadily over time. They now welcome more than 20 attendees each month.

When you meet Amy and Lewis, you meet two very special people. Dedicated, committed, serious, humorous, caring and inspiring are just a few words that come to mind. Not only does this amazing couple



support each other, they bring a special brand of kindness to their SPOHNC Chapter.

Each year, in April, the Beilman's share their boundless energy inside the Community Center at Grand Haven, where they put together a very large event called Move to Music. The event brings together survivors, friends, families and folks from the Grand Haven Community for a high energy exercise class. The fun continues after class, with lots of raffles, bagels, juice and goodies. The Beilman's event is a fundraiser

for SPOHNC, and each year, they have exceeded their goal in terms of attendance and money raised. Pretty soon, Grand Haven will need a bigger community center to accommodate the event!

Next month, we wish Amy and Lewis as well as all of those who they have nurtured and inspired along the way, a very Happy

5<sup>th</sup> Anniversary. Thank you for all you do for those who come to you seeking the support and care that you so willingly offer. Here's to the next 5 years!!

### Share Your Great News!



Is your SPOHNC Chapter celebrating a milestone? Are you?

**SPOHNC wants to share  
YOUR great news!**

**Send it to [info@spohnc.org](mailto:info@spohnc.org)**

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## **A TIME FOR SHARING...** Tongue on Wry Hold the Chemo

For over two thousand years history has been separated into two major divisions: "BC" and "AD". For most of us this has worked fine. For others however, a major life-changing event has caused us to pause and establish an additional "before and after." In 2005, during a routine dental exam, my long time friend and dentist advised me to see a specialist concerning "something questionable" that he noticed on my tongue. I took his advice, saw the specialist and was told there was nothing to be alarmed about, "but come back in 3 months for a follow-up exam." This went on for a year.

Every three months I went for a quick look, at which time a small sample was taken (a scraping) and sent out for analysis. In May 2006 the sample was reported to be "different" from the past few and it was recommended that I see a surgeon. As it turned out, I had a small (less than 1.5 mm) "in situ" growth on the right side of my tongue. It was described as "pre-cancerous," and was removed. I spent one night in the hospital and returned home. A few post-op tests, one or two uncomfortable days and the event was behind me.

Following this "episode," I visited a dental oncologist every three months for prophylactic exams involving palpation, visual observation and a tissue sampling every 6 months. Not a huge price to pay, since it seemed I had dodged a deadly bullet. Then on August 9, 2011, 5 years after my first encounter with oral cancer, the biopsy came back "hot." The cancer had returned with a vengeance. I was immediately sent to a head and neck surgeon who arranged for the standard tests, biopsies and consults with a plastic surgeon and a dentist specializing in oral reconstruction.

During the next 4 weeks, three more biopsies, and a PET CT were conducted concluding with a diagnosis of stage III cancer of the oral tongue. Things at this point began to move at warp speed. A few more visits with the doctors and surgery was scheduled. On September 26, 2011, a partial glossectomy and a neck dissection were performed. The head and neck surgeon removed the tumor, the lymph nodes on the right side of my neck and some salivary glands. The plastic surgeon replaced the

excised portion of my tongue with a radial forearm flap. Approximately 1/3 of my oral tongue was removed. When I awoke, I had 5 surgical wounds (including a tracheotomy) and more tubes than natural holes to accommodate them. Soon after, I realized my "before and after" date would now be September 26, 2011. "BT," before tongue, and "AT," after tongue. Not quite as universal as "BC" and "AD", but for me it was the turning point because my life had forever changed. I was in the hospital for a week. My wife and 2 sons were a constant source of encouragement and support. To this day I am convinced it was harder for them to get through that week than it was for me.

Upon returning home to begin recovery, I put my wife through a real trial by fire. The more uncomfortable I was the more irascible and ill tempered I became. She saved me, though given my abusive treatment of her, I don't know why. Today we look back on this "event" realizing that it actually made a strong relationship even stronger.

Adding to our little drama, 6 months prior to my tongue surgery I had a total knee replacement. No big deal...right? What was a big deal was, we had sold our house of 39 years, and were preparing to move to our new home in November which was "AT"+ 6 weeks. Now I am recovering from surgery and having to deal with packing, moving and all the anxiety that goes with relocating, all at the same time. Perhaps the added diversion was a good thing, as my focus changed from "me" to "us."

Enter the next step...post-op treatment. No chemo was recommended since the cancer was down graded to stage II because the lymph nodes were not involved. IMRT Radiation..."the gift that keeps on giving" was my punishment. I endured 36 daily sessions of being "poisoned." Was I sick! Somehow I found the strength to continue. Being stubborn or flat out stupid, I did not miss a day. I just wanted the treatments to be over as quickly as possible. December 30, 2011 was my last treatment and I have not looked back. I did keep the radiation mask, which was used to secure me to the table during exposure, as a reminder of

what was and how life can quickly turn.

In March of 2012 I had my first post-op PET-CT. The results came back negative for the tongue but due to what the doctors called a "serendipitous discovery" they discovered "something" on my right lung. It turned out to be cancer, unrelated to the tongue, and so I had a pulmonary lobectomy in May 2013.

It would be thoughtless of me not to acknowledge the team of exceptional doctors and nurses that treated me. The head and neck surgeon, the plastic surgeon, the radiation oncologist and the reconstructive dentist were extraordinary. This team of professionals has worked together for years as one cohesive unit with one goal, seeing that the patient has the best outcome possible.

Onto the present...things are very good. The long-term effects of the radiation therapy are progressing nicely, thank you. I have spent a large fortune on dental care and am happy to say I have retained a few of my own teeth. My sense of taste is compromised, I have difficulty swallowing at times and my saliva is as thick as honey, produced in minimal amounts. I suffer from moderate tinnitus. I have sores in my mouth, which have yet to heal... but, I have not missed a meal. If you ever have the pleasure of dining with me I suggest you bring something to occupy your time because I eat very slowly.

Finally, while going through this ordeal everyone has maintained a sense of humor. It has been 5 years since my surgery and at times I still struggle with my speech and have swallowing difficulties. There are words I cannot pronounce properly. I am reminded of the time, when my wife and I were in the car with our grandson, who was 6 years old, and having his own speech issues. He and I were having a discussion when my wife turned to us and said she felt like she was in a Looney Tunes cartoon with Daffy Duck and Elmer Fudd (I was Daffy). We couldn't stop laughing.

Even now my close friends, who have all been a huge support, mispronounce words and mimic my speech when we are together. We laugh a lot about things that most others would not think is funny, but we are a group who believe that laughter is a strong healing force. Keeping perspective

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is vitally important. There are people far less fortunate than I. I wish for them all that I have...exceptional doctors, a loving supportive family, great friends, many laughs and the strength to move on and overcome what ever adversity crosses our paths.

~ jeffze@gmail.com



**Our readers want to hear  
YOUR STORY.**

**Inspire Someone Today.**

Contact Chris at SPOHNC  
at 1-800-377-0928 to find out how.

## CHAPTER FACILITATOR NEWS

### Head and Neck Cancer Patient Symposium

Stanford Health Care/Stanford Medicine held an all day Head and Neck Cancer Patient Symposium on January 21, 2017 at the Stanford University campus. The program was arranged by Heather Starmer of the Department of Otolaryngology, Head and Neck Surgery. Ms. Starmer is the Director of Head and Neck Speech and Swallowing Rehabilitation Center at the Stanford University Cancer Center.

The day long symposium included presentations by physicians, a dentist and other professionals directly involved in head and neck cancer surgery, immunotherapy drug development for head and neck cancer treatment, radiation oncology, reconstructive surgery, Stanford's SPOHNC Chapter Facilitator, Amy Bunnell, MSW, a nutritionist, two physical therapists and others involved in head and neck cancer. The morning sessions ended with a panel discussion in which the morning speakers

responded to questions from symposium attendees.

The afternoon sessions included additional presentations by physicians and other specialists involved in head and neck cancer. These talks were followed by a patient panel where head and neck cancer patients provided a summary of their head and neck cancer



experience, followed by a Q and A period where those patients responded to questions from attendees. The day concluded with another panel session consisting of the afternoon speakers chairing the afternoon Q and A session.

The symposium was well attended and Stanford Medical hopes to repeat it on an annual basis.

*Editors Note: This article was submitted by Jerome Young, survivor and Stanford, CA SPOHNC Chapter Support group attendee.*

## HEAD AND NECK CANCER NEWS

### Surgery and Radiation Yield Better Survival in Some Oral Cancer Patients

NEW YORK (Reuters Health) - Surgery and radiotherapy may be a better course than organ preservation with concurrent chemoradiotherapy in selected patients with oral cavity squamous cell cancer, according to Illinois-based researchers.

As Dr. Michael T. Spiotto told Reuters Health by email, "The benefits of surgery over organ preservation have been debated in patients with certain head and neck cancers. Using a large population-based study, we found that surgery and radiation was associated with improved survival compared to chemotherapy and radiation for patients with advanced mouth and tongue cancers."

For the study, online April 20 in JAMA Otolaryngology-Head and Neck Surgery, Dr. Spiotto, of the University of Chicago, and colleagues examined data from 2004 through 2012 on 6,900 patients with stage III to IVA disease.

In all, 4,809 were treated with surgery followed by postoperative radiotherapy and the remaining 2,091 received

chemoradiotherapy (CRT). Median follow-up for the entire group was 23 months. However, surgery patients were followed for longer than the CRT group (25.6 vs. 17.3 months).

Among other differences were that the CRT patients were more likely to be older, to have been treated before 2007 and to have more comorbidities. Propensity-score matching was used to identify groups of patients with similar clinical variables.

Three-year overall survival was significantly greater in surgery patients (53.9% vs. 37.8%). This was also the case after propensity-score matching (51.8% vs. 39.3%). There were similar findings in patients with T3 to T4a tumors (49.7% vs. 36.0%), but in those with T1 to T2 tumors the difference was not significant (59.1% vs. 53.5%).

Among limitations of the study, say the researchers, is that "a substantial number of patients were excluded because of incomplete or inaccurate information, noncurative treatment intent, and disease

that was in situ, early stage, or unresectable."

The fact that the surgical approach was associated with improved survival, concluded Dr. Spiotto, "further supports the use of surgery and radiation in this group of patients."

###



**Where flowers bloom,  
so does love...**

Photo courtesy of caregiver, PJ Jordan

## CHAPTER FACILITATOR NEWS

### SPOHNC Middletown, NY Chapter Facilitator Sara Sargente, RN, OCN, Wins CURE®'s 2017 Extraordinary Healer Award

Nursing is simply in their blood. A winner and two finalists, honored at a May 4 ceremony celebrating *CURE*® magazine's 2017 Extraordinary Healer Award for Oncology Nursing, were each inspired in childhood as they watched their mothers and/or grandmothers go off to work every day, committed to shepherding patients through their illnesses.

Today, these women are inspiring others by going above and beyond the line of duty in their roles as oncology nurses. In essays by patients or their families, as well as by colleagues, these nurses and nearly 50 others were cited for offering life-changing compassion, expertise and helpfulness.

An audience of 1,000 was on hand to learn that Sara Sargente, RN, OCN, had won the award. The announcement came during a dinner and ceremony in Denver, held in conjunction with the annual congress of the Oncology Nursing Society (ONS). The event featured a keynote address by actor Patrick Dempsey, founder of the Dempsey Center, which provides supportive services to those affected by cancer.

Sargente is a nurse navigator for patients with head and neck cancer at Orange Regional Medical Center, in Middletown, New York.



In addition to offering comprehensive support to this population of patients who often face quality-of-life difficulties, she has become certified in blood management to meet the needs of the Jehovah's Witness community, whose members do not allow the use of blood products during surgery. In her free time, she runs a SPOHNC Chapter support group and an ONS chapter that raises funds for the basic needs of lower-income patients.

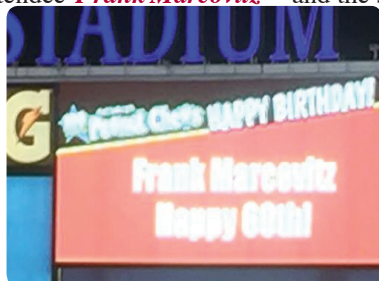
Sargente won a spa package at the Hyatt Regency Huntington Beach Resort and Spa, in California. The essay about her will be featured in an upcoming issue of *CURE*®. "Sara Sargente exemplifies what it means to be an extraordinary healer who goes above and beyond the call of duty to help patients, their families and health care co-workers," said Michael J. Hennessy, Jr., president of Michael J. Hennessy Associates, parent company of *CURE* Media Group, in announcing the winner. "Oncology nurses have very challenging jobs that blend specialized medical knowledge with a passion to provide comfort, education and advocacy to patients undergoing complicated, and sometimes long-term, treatments for the disease." Also honored during the ceremony were the two finalists, whose nomination essays were read by the patients or colleagues who wrote them.

Recognizing Unsung Heroes Since

### SPOHNC Is Celebrating YOU!

Through the power of social media, SPOHNC was alerted to a very special birthday in the month of May. Thank you Facebook (and the New York Yankees!) for letting us know that Survivor and SPOHNC Syosset Chapter attendee **Frank Marcovitz is turning 60!!!**

Here's what Frank's beautiful and very thoughtful wife, Carrie, did for him, to celebrate this great milestone birthday. Frank was at a recent home game at Yankee Stadium, and this is what he saw!!



**Happy 60<sup>th</sup> Birthday Frank!**



We truly can't believe you are turning 60. Your youthful spirit, and your zest for life, your love of biking, skating, volleyball and especially dancing have kept you young at heart. You inspire us all with your courage and the strength of an "Iron Man."

the inception of the Extraordinary Healer Award for Oncology Nursing in 2007, more than 1,000 nurses have been nominated. The finalists and essayists honored have included men and women, adults and children, representing a variety of cancer centers and hospitals in a host of states. Sargente was nominated by a colleague, Jayne O'Malley, RN, B.S.N., OCN, a lung cancer patient navigator and manager of navigation services at Orange Regional Medical Center. "When patients are diagnosed, they are extremely anxious, and when Sara meets them during her consultation, her calming influence and caring attitude shine," O'Malley wrote. "Head and neck cancer often affects the ability to eat, drink and speak, and a person's appearance. When you see how comfortable and cared for Sara makes patients feel, it is truly what the essence of being a nurse is all about." In accepting the award, Sargente said she considered herself a representative of "all oncology nurses out there who all know that oncology nursing is a passion and a love done with compassionate hands and hearts for the real heroes: the patients.

She added that, "now that my dad was recently diagnosed with malignant melanoma, I truly see the importance of what we do as nurses. I dedicate this honor to my dad and to all of our patients going through their cancer journey."

*Editors Note: This article was written by Beth Fand Incollingo and reprinted with permission from CURE. Originally published May 5, 2017.*



**Tell us about your Birthday so we can Celebrate YOU!!!**

*Since this is our last issue before the Fall, your Summer birthdays will be acknowledged in the September issue of "News from SPOHNC."*

*Send your birthdays to [info@spohnc.org](mailto:info@spohnc.org) or call us at 1-800-377-0928.*

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## Calling All SPOHNC Chapter Facilitators

Hi SPOHNC Chapter Facilitators! I'm Richard Boucher, SPOHNC Chapter Facilitator here in Medford, Oregon. I'm a grateful 17 year survivor of a stage 4 throat cancer and fortunate 17 year member of the SPOHNC family!

I'm working with SPOHNC Executive Director, Mary Ann Caputo and Outreach Administrator, Chris Leonardis of our national SPOHNC office to support the wonderful work the Chapter Facilitators do on behalf of our attendees in our 130+ chapters nationwide. We hope to enrich the services and deepen the connection between our SPOHNC Chapters, attendees and the national SPOHNC organization.



One idea that came out of brainstorming with Mary Ann and Chris was to create a Facebook group for Chapter Facilitators where we can:

1. Share best practices and ideas on creating awesome, supportive, and loving chapter meetings and events.
2. Grow national SPOHNC membership and support from our local chapter attendees.
3. Share news about SPOHNC and the progress that's being made daily in the fight against cancer.

Our Facebook group is now up and running and is called "SPOHNC Chapter Facilitators." It's a closed Facebook group, exclusively for Chapter Facilitators and Co-Facilitators, and each Chapter Facilitator

should have received an email and Facebook invitation to join. We've got over two dozen members so far and we're looking forward to all Chapter Facilitators who are on Facebook joining us! I'll be resending invitations out again soon in the event you missed the earlier ones. Meanwhile, Chapter Facilitators can go to Facebook, search on "SPOHNC Chapter Facilitators", and click on the

JOIN link. As the group administrator I'll receive your request and approve your membership. Of course, if any of your Chapter attendees have ideas to contribute to this conversation and to enriching SPOHNC, we welcome their input and you, as their Chapter Facilitator, can share their thoughts and ideas on the Chapter Facilitator page.

I hope you'll join Mary Ann, Chris, and myself in the SPOHNC Chapter Facilitators Facebook group and contribute to growing the services provided by our fantastic network of SPOHNC Chapters!

SPOHNC Chapter Facilitators are wise, kind, creative and loving! Let's share our best practices and make SPOHNC even greater and more fantastic than it already is!

Sincerely,

*Richard*

Richard Boucher  
Medford, Oregon  
SPOHNC Chapter Facilitator

*Photo courtesy of Survivor and SPOHNC Syosset, NY Chapter attendee, Brian McMahon*

**Hope is the thing  
with feathers  
That perches in the soul,  
And sings the tune--without  
the words,  
And never stops at all**

*~Emily Dickinson*



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**Broad stripes and bright stars.... gave proof....**

**that our flag was still there.**

**Broad stripes and bright stars ....**

**gave proof .... that our flag was still there.**

**Veteran**

I was a proud veteran  
That served my country well  
To those that would listen  
I had many stories to tell.

We fought for America's freedom  
In far away places on foreign land.  
Wherever the battle for democracy raged,  
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And the right to remain free.  
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We would gladly have given our life.  
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Lynne Carey  
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Compiled and Edited by Nancy E. Leupold, Survivor, Founder & President Emeritus  
Visiting with friends or family this summer? Take along this delectable appetizer and delicious  
dessert idea. You'll be the hit of the get-together!

### Sausage and Cheese Balls

(From Volume Two)

- 1 lb. sausage meat
- 1 lb. grated sharp cheddar cheese
- 3 c. Bisquick
- ¾ c. water

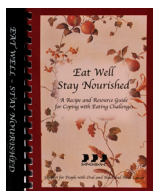
Cook sausage in large frying pan. Cool. Add cheese, Bisquick and water and mix well. Roll into 1 inch balls or smaller if preferred. Place on cookie sheet 2 inches apart. Bake at 400 degrees for 12 – 15 minutes or until puffed and brown. If freezing, cook only 10 minutes. Serves 18 to 20. 237 calories/serving.



~ Dorothy Brown, NY

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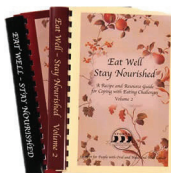
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### Fresh Strawberry Mousse

(From Volume One)

- 4 c. sliced strawberries
- 6 Tbsp. cornstarch
- ½ to 2/3 c. sugar
- ½ c. fresh lemon juice
- 1 Tbsp. grated lemon rind
- ½ pint heavy cream, whipped or 1 c. firm yogurt, stirred until smooth

Place strawberries in medium sized saucepan. Cover and cook over medium heat for 5 to 8 minutes or until it looks like soup. Pour into medium sized bowl and set aside. Combine cornstarch, sugar and lemon juice in the saucepan and whisk until uniform. Pour still hot strawberry “soup” back into the cornstarch mixture, whisking constantly. Return the saucepan to stove and cook over medium heat, stirring constantly until thick (about 5 minutes). Remove from heat and add lemon rind. Pour back into bowl and cool to room temperature. Puree until smooth in food processor or blender, return to bowl. Cover tightly and chill until cold. Fold in the whipped cream or yogurt and serve. Yields 8 (1/2 cup) servings. 203 calories/serving.

~ Nancy Mazur, NY



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## HEAD AND NECK CANCER NEWS

### *Swallowing Exercises Can Improve Quality of Life for Head and Neck Cancer Patients, Study Shows*

May 4, 2017 - While patients with head and neck cancer are likely to experience difficulty swallowing after undergoing intensity-modulated radiation therapy (IMRT), Lynn Acton, MS, CCC (SLP) says the use of swallowing exercises can drastically improve muscle movement for these patients both during and after radiation therapy (RT).

In a study conducted by researchers at Dana-Farber Cancer Institute and Brigham Women's Hospital, patients with head and neck cancer who underwent RT in a 2-year period were evaluated for swallowing difficulty with a video swallow to score stricture and aspiration. Of the 96 patients evaluated who received IMRT once daily, 32% had some aspiration after therapy, while 37% had evidence of stricture following RT.

Studies are currently ongoing to explore the utility of swallowing modalities for these patients. For example, an interventional, randomized, multicenter phase III trial is comparing early-active swallowing therapy versus nonspecific swallowing management (NCT02892487). Researchers are conducting the study to determine that early-active swallowing therapy can improve the quality of life of patients undergoing RT for head and neck cancer.

Additionally, a behavioral questionnaire is evaluating adherence to preventative swallowing exercises and the reasons why patients choose not to follow them (NCT03010150). Patients will complete the questionnaire at baseline and again at 6 months following RT that will discuss adherence to swallowing exercises.

Acton, a lecturer in surgery (otolaryngology) and speech pathologist at Yale School of Medicine, discussed the significance of swallowing modalities for patients with head and neck cancer during and after RT in an interview with *Targeted Oncology*.

**TARGETED ONCOLOGY: What is the benefit of doing these swallowing exercises for this patient population?**

**Acton:** I spoke about prophylactic exercises for swallowing for patients with head and neck cancer who are undergoing RT. We have found that if we keep the muscles mobile during the treatment, there is less fibrosis of the muscles. If the patients don't have fibrosis, they are able to move better and have better swallowing

function. During the treatment, patients will have some pain. We try to manage that and do things like a mouthwash to numb the area before they do these exercises.

It is more important to keep the muscles mobile because, when a joint like your jaw becomes immobile, the cartilage becomes thinner and the joints become inflamed and painful. If we keep the muscles moving, then the function is much greater. We like to [continue] to do the exercises after treatment, because RT can continue to contract the muscles over time. Therefore, patients do the exercises several times during the day and after treatment, too.

**TARGETED ONCOLOGY: Have there been any advancements in this field that have increased the quality of life for these patients even further?**

**Acton:** It is basically a lifelong thing at this point. For young patients, they say they feel relief after doing the exercises. Some of them [are simple] neck exercises, [such as] neck rolls. I do try to tag it in with something that they are already doing during the day. On their smartphone, I'll put an [alarm] that reminds them to do their exercises on the way to work, or maybe [while] they are reading a newspaper. I [put the written exercises] in the memos section [of their phone] to explain the exercises. Doing those things makes it a positive result. For the patients who do the exercises, we notice that they're able to maintain their oral opening. Normally, you should be able to put 3 fingers in your mouth.

When I started, I was seeing patients after RT because we didn't know it was important to keep these muscles mobile [during treatment]. They would be at a 1-finger opening and then we would have to work to stretch the muscles. I've also talked to patients after completing their [swallowing exercises] and they no longer have food sticking in their throat. They do work.

**TARGETED ONCOLOGY: What impact does prophylactic**

**swallowing exercises have on patients?**

**Acton:** Well, not everybody is compliant, so we tell them what the negative effects are of not doing the exercises. Some patients have to get a feeding tube because they are not maintaining hydration.

If you do the exercises, you can maintain good swallowing function and [function of the] muscles not only for swallowing. [They also help for] speech; some of the patients will have radiation and have very hoarse voices. I will have to counsel them on how to talk without straining. Their vocal chords become swollen during RT. We teach them how to talk gently so they don't do further damage to the chords.

**TARGETED ONCOLOGY: How should specialists handle adherence to these exercises?**

**Acton:** It is most important for patients to do the exercises when they least feel like doing them. We want you to take the mouthwash, do the exercises, and if I see the patients I explain to them that this is a very intensive treatment. This [radiation] treatment works, but if you don't do the things I am going to ask you to do, you are going to have disability after the treatment is done and we want to prevent that.

You have to see the patient frequently. [Seeing] them during RT and after the treatment would be ideal, because patients get a lot of encouragement. I will explain to them that I have seen [other] patients and evaluated their swallowing, and [if it is] perfect and it is because they did the exercises. I also let them know that before we do the exercises, patients will have to increase the oral opening.

**TARGETED ONCOLOGY: Are there any other types of exercises in addition to prophylactic swallowing that are worth mentioning?**

**Acton:** We start with the mouth opening. Today, we are seeing a different population of people versus in the late 80s—it was a lot of type A-personality men and they sometimes found that [these exercises] were hard and [thought that] it was going to be better. It was the complete opposite.

[We watch them do the exercises to](#)

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move the muscles in the neck. Even just a simple, hard swallow can be done every time they eat or drink something, gargling, extreme-yawn positions, and moving the back of the tongue.

The head and neck area is a very narrow area, so I do tailor the exercises to the patient and [explain to them] what they might expect. What can you do if you feel the food sticking in your throat? You can swallow hard; you can swallow twice. I do explain to them the specific things they should do if these things happen. Generally, for anyone who

is having RT [in this area] you want them to be able to move their neck and swallow — the RT the beams hit various points. **TARGETED ONCOLOGY: What are the main points you hope the community oncologists took away from your lecture and what does the future hold?** **Acton:** In the future, I hope that patients will be able to see these professionals more frequently. It is just important that we see these patients and that they are treated. These exercises are very easy to do - patients should not be afraid of doing them.

## HEAD AND NECK CANCER NEWS

### Putting a Name on the Impact of Cancer Treatment Costs

*OncologyNurseAdvisor - May 2, 2017 -* For many cancer patients, the financial toll of treatment may impact their household finances for years.

As most people who work in oncology are aware, the costs of cancer treatments continue to increase, with many new treatments costing more than \$10,000 a month. Patients bear an increasing proportion of this cost, typically in the form of copays, deductibles, or the Medicare “donut hole.” These increased costs affect both patients receiving oral chemotherapy and those receiving parenteral treatments.

One 2014 survey found that nearly one-fourth of insured adults younger than 65 years paid 10% or more of their household income on health care costs. Additionally, the patient’s household finances may be impacted by the loss of income due to a patient or caregiver’s need for time off from work due to the illness or caregiving needs.

For many cancer patients, the financial toll may impact their household finances for years after they have completed treatment. Financial toxicity is one of the more common terms used to describe the impact of cancer, cancer treatments, and long-term effects on a patient’s (or their family’s) finances. Some other terms you may see include financial distress, economic burden, and financial hardship.

Awareness of financial toxicity in the

medical and oncology community has increased over the last several years. Some national organizations are calling for a value-based framework (the drug’s cost would be at least partially based on the magnitude of its benefit to patients) in drug approvals and pricing. Other organizations are focusing on health care reform to minimize the costs to the patient. Many emphasize the need for an up-front conversation with patients about treatment costs, and to include the financial impact in the conversation when health care providers counsel patients on the adverse effects and benefits of a proposed treatment course.

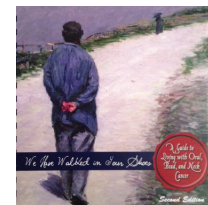
To facilitate these conversations, the National Comprehensive Cancer Network (NCCN) began including “evidence blocks” in their oncology treatment guidelines. These evidence blocks are designed to call attention to the affordability, efficacy, and safety of a treatment option, as well as the type and consistency of data supporting use of the regimen (eg, if multiple well-designed trials have shown a benefit to using the regimen or if it is based on a single, small study).

Because the problem of financial toxicity is multifaceted, there is no easy answer for how to minimize the impact of this on patients. Nurses play a key role in educating and advocating for their patients regarding financial and other toxicities.

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~ Jon T.

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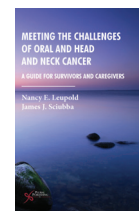
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