



# SPOHNC

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER | EST. 1991



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for a great cause!**

We are forever grateful to the Rick Agee Foundation for once again sharing the proceeds from the Annual Rick Agee Memorial Golf Outing with SPOHNC.



**Fore!!!!**



## Who is Fred??

Find out on page 6.

## From the Other Side of the Stethoscope

Read about a survivor who understands the value of sharing her journey with others. Turn to page 10.

## Understanding Radiation Fibrosis Syndrome

Michael Stubblefield, MD

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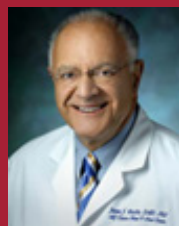
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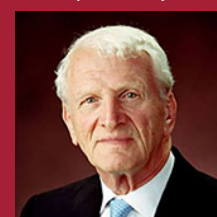
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Chris Leonardis

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# Understanding Radiation Fibrosis Syndrome in Patients with Head and Neck Cancer

Michael Stubblefield, MD

## Head and neck cancer, even when cured, is commonly associated with long-term issues

Head and neck cancer (HNC), even when cured, is commonly associated with long-term (issues that start with treatment and continue) and late effects (issues that arise months or



years later) of treatment. Most of these problems are related to treatment, particularly surgery and radiation therapy (RT). Those associated with surgery usually start right after surgery but can worsen over time. Disorders related to RT, on the other hand, may not develop for months or even years after treatment.

RT is a critical component of the treatment of many HNCs. Unfortunately, RT is a double-edged sword responsible for many of the issues faced by HNC survivors. Radiation not only kills fast-growing cancer cells; it also damages the normal body cells that are in the radiation treatment field (the part of the body targeted by radiation). This damage involves poorly understood mechanisms that ultimately result in abnormal deposits of fibrin (a normal body protein) and damage to the small blood vessels feeding the affected tissues. This process is called radiation-induced fibrosis (RF). The problems that result from RF are known as radiation fibrosis syndrome (RFS).

To understand RFS it is important to understand a little about how radiation is given. The area of the body subjected to radiation is known as the radiation treatment field. In general, the part of your body where the primary tumor is (or was before surgery) and the lymph nodes of the neck are treated with RT. The radiation is given in small doses called “fractions” that are totaled up to a maximal dose of radiation. The doses used for HNC are very high – up to 7,000 cGy for the primary tumor and 5,400 cGy for the neck. These high doses aren’t arbitrary, they are based on years of research trying to get the best cure rates with the lowest amount of side effects. Even though sophisticated radiation techniques allow for precise targeting, the tissues surrounding where the cancer is (or was) are included to help ensure that any microscopic deposits of cancer are killed. This means that the bones in the neck, spinal cord, nerves, ligaments, tendons, fat, skin, blood vessels, lymphatic channels, glands, and any other tissue in the field can be damaged by radiation.

The problems resulting from this damage vary considerably between patients with some having minimal and others having significant consequences. Because the effect of radiation can worsen over time, recognizing them early and managing them is the key to living your best life.

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## Symptoms of Radiation Fibrosis Syndrome

Common symptoms of RFS include pain, stiffness, loss of range of motion, weakness, speaking and swallowing issues, dry mouth and abnormal swelling called lymphedema. These issues often cluster together and it is not uncommon for survivors to have several of them. This article will discuss some of the common issues and how to treat them.

### Neck fibrosis

Some HNC survivors will report having “fibrosis of the neck.” Such patients often experience tightness, hardening of the skin and underlying tissues, stiffness, loss of mobility, swelling, spasms and pain. Neck fibrosis is part of the spectrum of RFS and results from damage to soft tissues of the neck including the skin, fat, muscle, tendons, and ligaments. Damage to the nerves can cause nerve pain and contribute to spasms of the muscles. Spasm of the neck muscles can cause tilting of the head – a phenomenon called “cervical dystonia.”

The mainstay of treatment for all the issues resulting from neck fibrosis is physical therapy. The goal of therapy is to improve, and very importantly, maintain the range of motion of the neck, shoulders, mouth, and other tissues in the treatment field. Improving posture and strengthening affected muscles is also of paramount importance. One of the most important techniques used by the therapist is myofascial release (MFR). MFR is a relatively specialized technique that requires considerable training, knowledge, and skill to get the best results. For some patients, MFR can help relieve muscle spasms and pain, improve blood and lymphatic flow, and improve range of motion.

Other important techniques include postural retraining, neuromuscular reeducation as well as general strengthening and conditioning exercises. Because the effects of radiation can worsen over time, it is critical to learn a home

exercise program and do it daily to slow and minimize loss of function. Patients will often need to return to therapy every few months to get hands-on treatment and ensure they are doing the most effective home exercises.

Muscle spasms can occur anywhere in the radiation field and even outside of it if certain nerves passing through it are affected. It is common for the muscles in the front of the neck to spasm painfully with certain motions or for no obvious reason

at all. The side where the cancer was is most likely to spasm, but it can happen on the other side as well. While any neck muscle can spasm, two in particular, namely the sternocleidomastoid and scalene muscles, are thought to be the main culprits. Treatment with physical therapy using the specialized techniques described above are often very helpful but may not be effective enough for all patients. For patients who continue to have spasms after optimal therapy, nerve stabilizing medications (i.e., pregabalin (Lyrica) or gabapentin (Neurontin)) may be helpful. Common side effects of these medications include dizziness, sleepiness, and other issues. While most patients don't experience these symptoms, for others they are bad enough that they can't tolerate the medicine. For those where physical therapy and medications didn't produce the desired result, injection of the affected muscles (usually sternocleidomastoid and scalene) with botulinum toxin can be extremely helpful. This is particularly true for patients with cervical dystonia. Not all physicians, even those who perform similar injections, are comfortable performing botulinum toxin injections into the neck of HNC survivors.

living your best life  
beyond cancer  
is the key  
to surviving well

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When effective, botulinum toxin injections will wear off in 6-12 weeks and need to be repeated. It is rarely, if ever, a good idea to inject the muscles in the back of the neck, even if they are painful and spasming, because it can weaken the neck and cause difficulty holding up the head. This is called “dropped head syndrome” or DHS.

### **Neuropathic Pain**

Not all neck pain in HNC survivors with RFS is from muscle spasm. Damage to the nerves from surgery and/or radiation can cause them to fire abnormally and send pain signals. This is called neuropathic pain. Neuropathic pain is often experienced as sharp, burning, tingling, like pins and needles. It can be associated with reduced sensation or numbness. For some, even lightly touching the skin can trigger the pain. Neuropathic pain and muscle spasm pain are commonly experienced together.

Common locations patient experience neuropathic pain is in the lower jaw and front of the neck. It is also possible to experience pain in various parts of the arm when the nerves going through the radiation field are affected.

Treatment of neuropathic neck pain can involve physical therapy and the use of MFR to stretch the fibrotic tissue around the damaged nerves. Nerve pain medicines such as pregabalin (Lyrica), gabapentin (Neurontin) and duloxetine (Cymbalta) are very often needed to get the best relief.

### **Getting Help**

Because there can be a years-long delay from treatment to when problems start, clinicians often do not recognize the relationship of a problem to prior radiation. Conversely, not all problems experienced by HNC survivors are radiation related. Making the correct diagnosis may require a specialist with experience diagnosing and treating cancer survivors. It is critical that HNC survivors strongly advocate for themselves by asking

their doctors the simple question “can this be related to radiation.” Getting a second opinion from a specialist is never a bad idea for patients who still suspect prior radiation is contributing to a given issue.

Unfortunately, not all healthcare clinicians understand radiation late effects. This includes not only physicians, but physical therapists and others. Finding clinicians who understand how radiation affects the body is the first step in getting the best outcome. Patients treated at some academic medical centers may already have a team of knowledgeable rehabilitation clinicians they can be referred to. Those treated in the community oncology setting may have to do some searching to find the closest clinicians with the knowledge and skills to help them. While physical therapy is best done “hands on” in most cases, telerehabilitation has become an option for patients that live too far away or have transportation or financial limitations. Assessment by a physician with knowledge of the late effects of radiation has also been made easier by telehealth and it should be considered by patients who cannot find a local physician to help them.

With optimal evaluation and management, most HNC survivors can live long, functional, enjoyable, and meaningful lives. Just as with getting older, there may be some limitations that creep in as time progresses. Understanding the effects of radiation and assembling the best team to help you live your best life beyond cancer is the key to surviving well.

Editor’s Note: Dr. Michael D. Stubblefield is the Medical Director for Cancer Rehabilitation at Kessler Institute for Rehabilitation, National Medical Director for Select Medical’s ReVital Cancer Rehabilitation Program and National Medical Director for Complex Medical Rehabilitation for Select Medical’s Inpatient Rehabilitation Hospital Division. He is the former Chief of Cancer Rehabilitation at Memorial Sloan-Kettering Cancer Center and a Clinical Professor in the Department of Physical Medicine and Rehabilitation at the Rutgers New Jersey Medical School. Board certified in Physical Medicine and Rehabilitation (PM&R), Internal Medicine, and Electrodiagnostic Medicine, his primary clinical expertise is in the identification, evaluation, and rehabilitation of neuromuscular, musculoskeletal, pain, and functional disorders resulting from cancer and its treatment, particularly those caused by radiation and neurotoxic chemotherapy.

# FRED



Throughout this period, I was supported by my loving wife, Barbara, who every day commuted 16 miles each way by bus from our apartment on the north side to the U of Chicago to be by my side. She recruited blood donors; kept the family up to date; administered the feeding tube; and lovingly cared for me. During this period, Barbara also put her feelings into poetry. We wrote a little book that reveals both love and suffering in Barbara's words.

It is September 2022. I am cured.

Fred W.  
wackerle@aol.com

In May 2015 I felt pain in my ears every time I swallowed. Probably a sore throat. My doctor prescribed an antibiotic, but it didn't work.

After several months I visited an ENT doctor in Tucson, who scoped my throat, and said "you have a tumor at the base of your tongue, and it's probably malignant." I went to the University of Arizona for a biopsy that confirmed cancer.

Our dear friend Renate had recently undergone cancer treatments at the University of Chicago and she and her husband Jack introduced us to Drs. Daniel Haraf, Vicky Villaflor and Elizabeth Blair who were teamed in a new "Optima HPV Clinical Trial." I became enrollee number 12. The treatment protocol began with 9 weeks of chemotherapy to reduce the size of the tumor.

Following that came a series of chemoradiation treatments: 5 days in the hospital for a 24 hour chemo drip, and two daily radiation treatments over 5 days. Go home to recover for 5 days then return to the hospital again. This cycle was repeated 5 times over ten weeks. It was brutal, I went into sepsis. I thought I had died. I recovered. The mouth sores and pain were too great, and I was on a feeding tube for 6 months. I had 10 units of blood transfusions. I lost my taste. Treatment ended Labor Day 2015.

SHARE *your*  
JOURNEY

with our readers...

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or at [info@spohnc.org](mailto:info@spohnc.org) to find out how.

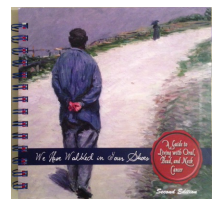
You can find additional stories by going to  
SPOHNC's website at  
[www.spohnc.org](http://www.spohnc.org)

## SPOHNC's RESOURCES

**We Have Walked In Your Shoes: A Guide to Living With Oral, Head and Neck Cancer**  
- by Nancy E. Leupold & James J. Sciubba, DMD, PhD

DIGITAL EDITION available now on our website for \$7.99

PRINT EDITION \$14.95 includes shipping and handling



For Bulk order Discount Pricing contact SPOHNC at 1-800-377-0928  
or email us at [info@spohnc.org](mailto:info@spohnc.org)

# Rick Agee Memorial Golf Outing

It was a beautiful day for 18 holes, as the Annual Rick Agee Memorial Golf Tournament began on June 24th. The tournament, in its 7<sup>th</sup> year, has been held every year for the benefit of SPOHNC. This year's event raised more than \$15,000!

This year's outing was held under the direction of the newly formed Rick Agee Foundation, so it was the inaugural effort of the Foundation, and a well done effort for sure! The Foundation is lead by its Board of Directors including Kerry Agee, E.L. Biggerstaff, Bill Smith, James McKee and Dirk Tyneke. Janie Agee is the treasurer, and Ben Agee is their legal counsel. The Foundation is indeed a family affair, and this is a family that is very much beloved by SPOHNC.

The tournament was held once again at The Cliffs Resort on Possum Kingdom Lake. 66 golfers arrived early, and stayed late. In total there were 72 people who attended the event

to support it in some way. After some very early golf, everyone was treated to a wonderful lunch. Golf prizes followed. The tournament winning team was Adrian Muhlstein, Seth Muhlstein, Jeff Frasier and Greg Kilpin. They were excited to receive their honor once again, as this was the fourth year in a row they have won. The handicap system was utilized this year, and they won by .1 strokes. Their net score was 51.2 and second place was 51.3.

There were a few challenges that tried to take the outing "off course" this year, but perseverance and a love of the game, and Rick, prevailed, and the day was a huge success! There were 22-hole sponsors and 13 very generous vendors who donated some amazing raffle prizes. Always popular, two of the biggest prizes were a \$1000 gift certificate to Seema Jewelry and a 3-night stay at Table Rock Lake in Branson. The raffle was outstanding as always, with Jack and Maryellen Mitchell taking the lead and organizing every detail.

There were several newcomers this year, but tournament regulars were honored and proud to be part of the day that started out many years ago. The crowd notably included 9 of Rick's college friends and some of their kids, along with 18 friends from high school and some of their kids. Rick was undoubtedly smiling down upon everyone all day long, pleased and proud as ever.

Plans are already solidified for next year's tournament date of June 24th,

so if you'd like to fly to Texas and play a game of golf to benefit a wonderful cause, let us know and we can put you in touch with Kerry and his family.

SPOHNC is forever grateful to Rick, for his love and support of SPOHNC, which he always kept in his heart with gratitude. Rick's brother, Kerry and the entire Agee family, and Jack and Maryellen Mitchell deserve a round of applause from the gallery, for their efforts and hard work in keeping this great event going. Your kindness, generosity and hard work do not go unnoticed, and we are honored to be the beneficiaries of the event, as well as becoming such great friends of the entire Agee family. Thank you all, from the bottom of our hearts. Another Hole in One!





# SPOHNC Syosset, NY Day Out

SPOHNC's Syosset, NY support group recently spent a sunny Saturday afternoon at West Hills County Park in Melville, NY, celebrating life, survivorship and the great outdoors. What a beautiful day for a picnic in the park! Entertainment was provided by the cloud formations, the dogs at the neighboring dog park and the stories shared by Marilyn and Wayne, Brian and Donna, Alice and of course, ever entertaining SPOHNC Syosset, NY Chapter Facilitator Frank Marcovitz and his wife Carrie. Check out the upcoming October newsletter for pictures from our next outing!



Doing something special with your SPOHNC Chapter support group? Meeting in person again? Send us your photos and a short story (with permissions) to be featured in a future issue!

## It's Apple Season!

### Applesauce Cake

Janet & Frank B. – North Carolina  
Volume 1, pg. 133

#### Ingredients:

- |   |  |
|---|--|
| <input type="checkbox"/> 1 c. butter or margarine | <input type="checkbox"/> 2 tsp. baking soda          |
| <input type="checkbox"/> 2 c. sugar               | <input type="checkbox"/> 3 ½ c. flour                |
| <input type="checkbox"/> 2 tsp. cinnamon          | <input type="checkbox"/> 1 c. walnuts, chopped       |
| <input type="checkbox"/> 2 tsp. cloves            | <input type="checkbox"/> 2 c. raisins                |
| <input type="checkbox"/> 2 tsp. nutmeg            | <input type="checkbox"/> Cherries, cut ¼ size pieces |
| <input type="checkbox"/> 2 c. applesauce          | <input type="checkbox"/> 2 eggs, beaten              |



#### Directions:

- ☐ Preheat oven to 350. In a large bowl, cream butter with sugar, cinnamon, cloves, and nutmeg. Add eggs and mix well. Add applesauce and continue mixing. Add baking soda and flour until well blended.
- ☐ Fold in fruit and nuts as desired. Bake at 350 in a greased and flour Bundt pan or tube pan for 1 ¼ hours until a toothpick inserted in the center comes out clean. Let cake cool slightly, then turn upside down onto a serving platter. Yields 16 servings.

#### Nutritional Information Per Serving:

- ☐ Calories 414(kcal), Total Fat 17(g), Saturated Fat 8(g), Cholesterol 54(mg), Sodium 285(mg), Carbohydrate 62(g), Dietary Fiber 2(g), Protein 6(g).



### Eat Well Stay Nourished A Recipe and Resource Guide for Coping With Eating Challenges

compiled by Nancy E. Leupold,  
Founder

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# Head and Neck Cancer News

## Clinical Trials and Immunotherapy for Head and Neck Cancers



Join us for a webinar where we will discuss the current head and neck cancer landscape, how clinical trials can help advance treatments, and the potential of immunotherapy for head and neck cancer patients.

Sponsored by SPOHNC and the Head & Neck Cancer Alliance, the webinar will feature a physician with specific expertise in head and neck cancers and a two-time head and neck cancer survivor. More information on our speakers can be found included below.

### Speakers

Ricardo Zwirtes, MD

*VP, Clinical Development @SQZ Biotechnologies*

Dan Paul Zandberg, MD

*Associate Professor of Medicine & Medical Oncologist/Hematologist  
@University of Pittsburgh Medical Center  
SPOHNC Medical Advisory Board member  
& News from SPOHNC author*

Jeffery Shoop

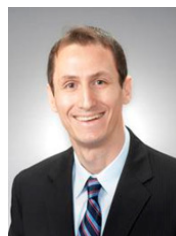
*Two-Time Head and Neck Cancer Survivor & SPOHNC National Survivor Volunteer Network volunteer & October 2021 Champion of Hope*

This webinar will be hosted by SQZ Biotechnologies, a clinical stage biotechnology company focused on unlocking the full potential of cell therapies for multiple therapeutic areas.

Wednesday, Oct 12, 2022 10:00 AM Eastern Time (US and Canada)

Register at:

[https://sqzbiotech.zoom.us/webinar/register/WN\\_sj49WA7CSiGIsoiFfAj8qw](https://sqzbiotech.zoom.us/webinar/register/WN_sj49WA7CSiGIsoiFfAj8qw)



“Thank you.

I value  
your  
printed newsletter  
and  
excellent efforts!”

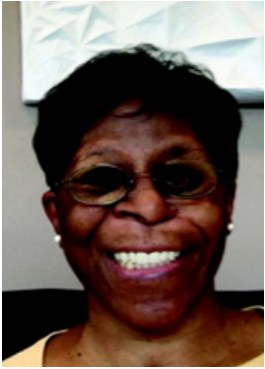
~ Patricia Z.

# September Champion of Hope

## Sharon Taylor

Our September Champion of Hope  
is one amazing woman

This month, SPOHNC is honoring a very special survivor who is near and dear to our SPOHNC hearts. We know that many of you know Sharon Taylor, either because you have been matched with her, attended her support group, or have interacted with her on our closed Facebook group. Sharon, a 23 year survivor, is amazing.



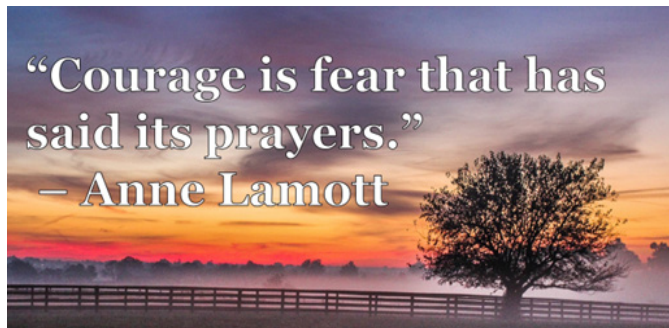
Sharon was a career medical oncologist. She saw and helped cancer patients on a daily basis. Little did she know that one day, she would be seeing cancer through the eyes of a patient. After her 1999 diagnosis and treatment for a very rare cancer called sinonasal undifferentiated carcinoma, Sharon came to SPOHNC seeking a way to help. She understood the value of sharing her experience with others along their cancer journey.

In 2016, Sharon became the Co-Facilitator for the Raleigh—Durham SPOHNC Chapter support group, alongside Lee James. This group has been active and remained active through Zoom meetings since the pandemic began. The group has finally resumed in person meetings.

In 2017, Sharon agreed to be a participant in a program that SPOHNC and Merck partnered on – a campaign called “With Love, Me.” For this program, cancer survivors wrote letters to themselves writing about what they as a

cancer survivor would have wanted their past self and others with a new cancer diagnosis to know at the time of diagnosis. The letters were shared in several different ways as part of this program. The culminating event was a program and a panel, presented in NYC just before Covid, in 2019, with Katie Couric as the moderator, and participants including cancer survivor Jim Kelly, of Buffalo Bills fame, among others. SPOHNC was invited to attend, and much to our surprise, we had the honor of meeting and spending time with Sharon and her dear husband, Willie. They had been invited by Merck, and flew up to NYC for a little extended stay.

2019 was a busy year for Sharon. She shared her cancer journey with SPOHNC’s readers in the



February 2019 issue of *News from SPOHNC*. That’s also the year that Sharon became a volunteer for SPOHNC’s National Survivor Volunteer Network. Since that time, she has supported more than a dozen patients who shared a similar diagnosis and treatment plan.

Sharon has been gracious in serving on several patient panels, providing a valued perspective to pharmaceutical companies and others who seek the expertise of a patient when designing research, or a campaign to raise awareness and support head and neck cancer patients and survivors. Most recently, Sharon agreed to be part of a special project that was produced by SPOHNC in collaboration with The Carleton Group. Hint - watch our website for something great - COMING SOON!

SPOHNC owes a debt of gratitude to Sharon, for always being there to help, support and provide hope and inspiration for those who come to us, and to her. It is our joy to honor this lovely woman, who continues to give so much of herself. We love you Sharon, and we congratulate you on being selected as our September Champion of Hope!

## CHAPTERS OF SPOHNC

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

*PLEASE NOTE: Some Chapters are not yet holding meetings in person due to COVID-19.*

Many groups have found other creative ways to support one another during this time of need.

Call to SPOHNC to find out more.



Send us your SPOHNC support group photo (with permissions) to be featured here in a future issue!

**SPOHNC**

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