

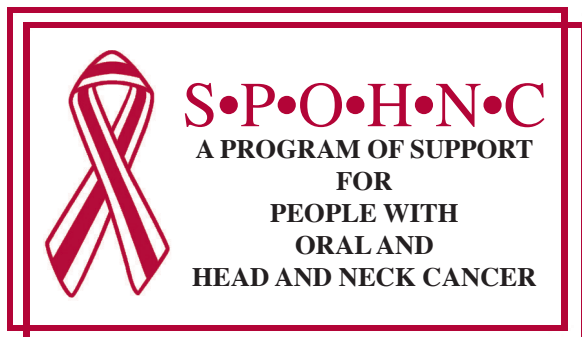
NEWS FROM S·P·O·H·N·C



VOL. 24 NO. 8

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

MAY 2015



Cancer Coverage Under Medicare

Danielle Kunkle

Medicare is our nation's health insurance program for people over age 65 and certain categories of people with disabilities. It provides a comprehensive set of benefits that includes both



inpatient and outpatient benefits, and these benefits include considerable coverage for the treatment of cancer. Your Medicare benefits are available to you at age 65 regardless of your current health. There are no exclusions or waiting periods on your Medicare benefits.

Medicare covers the treatment of cancer just like any other illness. Let's take a look at the basics of Medicare coverage before we expand on how it impacts cancer treatment specifically.

Basic Benefits

Your Medicare Part A benefits include inpatient hospital care, skilled nursing, some home healthcare services and hospice benefits. Think about Part A as your coverage of room and board – it provides payment for a semi-private room in a hospital or skilled nursing facility. The services you receive while you are in the hospital, will often fall under Part B.

Part B is considered outpatient care, but it actually covers many services that occur in the hospital too. Your physician visits and lab-work fall under Part B, as do surgery, ambulance and emergency benefits, diagnostic imaging, durable medical equipment, physical therapy and many other services. A number of cancer screenings, such as mammograms and colonoscopies fall under Part B as well.

In 2006, Medicare added a prescription drug program called

Part D. This is essentially a pharmacy card that you can purchase giving you access to retail medications as a copay or percentage instead of you paying the full price. Some oral medications related to cancer will fall under Part D.

Your Premiums for Medicare Coverage

Most individuals are "paid-up" for their Medicare Part A premiums when they age into Medicare. This happens because during your working life, your paychecks were taxed to pay for your future Medicare benefits. As long as you or a spouse have worked 40 quarters, or 10 years, during your lifetime in the United States, you will not have to pay any premiums for Part A.

Individuals who are new to the country or have not worked the necessary quarters to qualify for premium-free Part A may be able to purchase it.

Part B benefits have a monthly premium that you must pay. The monthly premium for Part B in 2015 is \$104.90 for most people. A small percentage of individuals also must pay an additional amount, called a premium adjustment, if their income exceeds certain thresholds. Some lower income individuals may also qualify for premium assistance with Part B if their income falls below certain annual levels. These are called Medicare savings programs, and you can learn more about that at the Social Security website: www.ssa.gov.

Finally, if you choose to enroll in Part D, you will also pay a monthly premium to the insurance company that you have chosen to provide your drug plan. The premiums for Part D vary widely and can range from plans as low as \$15/month to plans that exceed \$100/month. Each plan has a different formulary, and beneficiaries can enroll into the plan that best matches their medication needs.

Cost-Sharing for Medicare Services

It's important to understand that Medicare does not cover 100% of your medical costs. Both Part A and Part B require cost-sharing from you in the form of deductibles, copays and coinsurance.

For example, you will pay a \$1260 deductible for Part A inpatient hospital stays in 2015, and you will also be responsible for a considerable daily hospital copay if your stay exceeds 60 cumulative days. Under Part B, you will pay a small annual deductible of \$147, and then 20% of most services.

Of further concern is the missing Out of Pocket Maximum. Unlike other insurance you may have had through an employer in the past, Medicare has no out of pocket limit or cap to protect you from spending beyond a certain amount. The 20% share of outpatient services that you will pay goes on forever, and without proper supplemental coverage, you can end up with medical bills that you are unable to pay. For this reason, many individuals enroll in supplemental coverage to cover some of these gaps in Medicare.

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NEWSLETTER EDITOR

Chris Leonardis

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This brings us to a discussion of cancer treatment under Medicare, and what steps you can take to enroll in coverage that will give you peace of mind regarding any potential expenses for cancer treatment while you are on Medicare.

How Medicare Covers Cancer

Treatment of cancer under Medicare is no different than treatment for any other illness. Depending on whether a treatment falls under Part A, B or D, you will pay the cost-sharing as we have discussed above.

Here are some of the common services for cancer that Medicare services:

- Hospital care and surgeries
- Doctor visits, including second opinions
- Chemotherapy and radiation
- Durable medical equipment
- Prescription medications for chemotherapy
- Treatments for the side effects of cancer treatment, such as medications for nausea
- Some experimental treatments via clinical trials
- Skilled nursing facility care
- Home healthcare services
- Rehabilitative care
- Hospice care

You will be able to receive these services from any provider that participates in Medicare, which means access to over 800,000 providers across the nation.

Many of these services fall under Medicare Part B. As you are responsible for 20% of the costs of these services, it's fairly easy to see that cancer treatment can be expensive. Arranging coverage that will help you pay that 20% as well as other items like deductibles, can enable you to focus on getting well.

Medigap to the Rescue

Insurance companies began offering supplemental coverage for Medicare decades ago. These plans were called Medigap plans, and they still exist today to help you with paying for your cost-sharing under Medicare.

Medigap plans are offered by private insurance companies. The benefits are standardized, which means that insurance companies must include certain benefits mandated by the federal government. Each plan is labeled with a letter ranging from the letter A through the letter N, and you can choose the level of coverage that fits your needs and budget.

Fortunately, all Medigap plans cover the 20% cost-sharing that you would normally spend on Part B services. Since so many cancer treatments fall under Part B, any Medigap plan is going to reduce your worry that you would pay 20% of the cost for expensive chemotherapy and radiation, or the cost for surgeries

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related to your cancer. Many plans also pay for your deductibles due under Part A and B as well.

The most popular Medigap plan for many years has been Plan F. This plan pays all of the cost-sharing that you would normally incur. Plan F covers both deductibles and all of your cost-sharing and copays. This essentially feels like a first-dollar coverage plan. You will present your Medicare card and your Medigap card to any participating provider, and you will not owe anything. Your Medigap plan pays for all of your cost-sharing for covered services.

This plan can create considerable peace of mind for any individual receiving cancer care services such as a long course of chemotherapy. Regardless of the cost of treatment, Medicare will pay its 80% and your supplement pays the other 20%.

Perhaps most importantly, there are no networks related to Medigap. No matter which insurance company you choose for your benefits, you can receive treatment from any Medicare facility or provider anywhere in the nation. This lets you remain in control of where you receive your cancer treatment and be able to seek out the top physicians and providers in their respective fields.

Alternatives to Medigap

As you can imagine, Medigap plans are not free. You can shop for the plan that you are most interested in and get quotes to see which insurance company offers you the plan at the best rate. Depending on when you enroll and which state you live in, there are rules regarding your eligibility for Medigap, so you'll want to seek out an agent or broker who works with these plans to see if you can qualify.

If a Medigap plan is not affordable for you, you might consider a Medicare Advantage plan. Advantage plans are private Medicare plans that allow you to get your benefits from an insurance company instead of Medicare itself. Members receive their care from a select network of providers, and pay copays for services as they access their care.

Many people are comfortable with Medicare Advantage plans because they operate very similarly to group insurance plans that you may have been enrolled in during your working years. Typically there

is either an HMO or PPO network of doctors and hospitals, and you will need to receive your care from these providers in order to get the lowest copays for services. You can choose a plan that integrates your Medicare Part D benefits as well, making it easy to get all your benefits from one place.

Pros and Cons of Medicare Advantage

The upside to Medicare Advantage plans is that you pay only a limited copay or cost-share as opposed to 20% of all Part B services. These plans also have an Out of Pocket Maximum Limit to protect you. Under current Medicare law, this cap can be no more than \$6700 for in-network services. This means that even in a year full of high medical spending, you are not responsible for any medical costs which exceed \$6700. The insurance company must cover costs for covered services in excess of this maximum limit. It should be noted that this limit applies to medical benefits, and any Part D benefits have their own threshold.

Another upside is that the plans are quite affordable in many areas. Some plans, typically HMO plans, may even have a \$0 premium, which means you pay no monthly premium for the plan beyond the Part B premium that you already pay. You follow the network rules and just pay your copays and cost-sharing for covered services, which means you can pay as you go instead of forking over a big monthly premium for a Medigap plan.

These plans are also easy to gain access to. There is an annual enrollment period each Fall from October 15th – December 7th during which you can join any plan for a January 1 effective date, regardless of your cancer diagnosis. The only health question asked at enrollment time is whether you have end stage renal failure. As long as your kidneys are not failing and you live in the plan's service area, you can enroll into a Medicare Advantage plan and receive your Part A and B benefits through that plan, paying only the copays that are listed in the summary of benefits.

The potential downside to Medicare Advantage plans for people with cancer is that you must work within the plan's network to receive your care. Medicare Advantage PPO plans have some out of network coverage but you'll pay more for care at these facilities. HMO plans generally

do not cover any care out of network unless it's for emergency services.

Reputable oncologists in the nation are spread out among many cities and hospitals. You may, however, find yourself in a Medicare Advantage plan in which a leading specialist does not participate in the plan's network. These are all things you need to think about when choosing the type of coverage that you think will best suit you.

Keep in mind that the reason we buy health insurance coverage is not just for our access to doctors and hospitals right now. We also need to insure against future illnesses and plan for what type of coverage we feel will best suit us if we should develop a major illness like cancer down the road. Check with your principal physicians and hospital facilities to see which type of coverage they participate in. Choose a policy that will allow you access to any doctors or hospitals that are useful to you.

Beyond the Basics

Regardless of which type of coverage you choose for yourself, you will have ongoing policy needs once you are enrolled. Your agent or broker can help you with determining whether certain items fall under Medicare or your supplemental coverage. Here are some common questions and answers that our agency receives regarding cancer treatment under Medicare:

Can my coverage be dropped after a cancer diagnosis?

No. You will not lose your Medicare coverage or your supplemental coverage due to being diagnosed with any illness. You can only lose your coverage for failing to pay your premiums.

Which cancer care centers will I have access to?

Most hospitals and cancer centers participate in Medicare. If you have Original Medicare with a Medigap plan for your supplemental insurance, you will be able to seek treatment from any of these facilities. Ask the provider whether they accept Original Medicare to be certain.

If you enrolled in a Medicare Advantage plan, you can generally access the providers that are listed in your network's directory for your plan. Networks will usually be local within the counties close to your home or in some areas, across the state.

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Will my cancer medications be covered?

Most likely yes. Your Medicare Part B coverage will generally pay for medications administered by your doctor's office or cancer center. This includes medications that are given through an IV or administered as a shot, as well as some oral medications given to you at the doctor's office.

Some cancer medications that only come in an oral form are covered under Medicare Part D instead of Part B. This is why it is so important that you enroll in Part D even though it is considered "voluntary" coverage. You do not want to be uncovered for medications that treat cancer.

Should I consider an Obamacare health plan instead of Medicare?

No. Individuals who are eligible for Medicare do not qualify for the health plans under the Affordable Care Act. (And you wouldn't want one anyway because the cost of Medicare and supplemental coverage is generally less than what you would pay for an Affordable Care Act plan even if you could buy one.)

What if Medicare denies my treatment?

Most forms of cancer treatment are covered by Medicare. Make sure your physicians accept Medicare before you start treatment. If you receive a statement from Medicare or your Medicare Advantage company denying payment for a service you received, then you have a right to appeal that decision. Your explanation of benefits statement will clearly show you why a bill is denied, and provide you with information on how to appeal and where to send your appeal. Getting supporting documentation from your healthcare provider for why a treatment was necessary can sometimes help your case in an appeal.

There are 5 levels to the appeals process. If your initial appeal to Medicare is denied, you can then proceed to: 1) redetermination by the company that handles claims for Medicare, then 2) reconsideration by an independent medical review entity, called the Qualified Independent Contractor. If still denied, the claimant can 3) request a hearing before an administrative law judge and then finally he can 4) bring a lawsuit for judicial review in a federal court district.

Medicare Appeals Related to Dental Work

It should be noted here that people with head and neck cancer sometimes experience Medicare denials for dental work related to their cancer treatment. The problem stems from the fact that Medicare does not cover routine dental work. The Medicare Benefit Policy Manual states that claims for "items and services in connection with the care, treatment, filling, removal or replacement of teeth, or structures" are not covered.

The amount of money at stake is so significant that such denials have even led to lawsuits being filed against the Department of Health and Human Services. Extensive reconstructions or bone grafts followed by implants can be many thousands of dollars, perhaps even more expensive than the cancer treatment itself. When people can't pay, the oral surgeon is sometimes left to absorb the bill. If necessary, try to work out a financial plan with your physician or medical facility before treatment starts.

While the Medicare manual technically does allow for coverage of certain dental services that are related to cancer treatment, beneficiaries often have to prove that the dental service was "incident to and an integral part of a covered procedure or service performed by the dentist."

So for example, if you have teeth extracted in preparation for a round of radiation therapy, and the extraction does not occur at the same time as the radiation, you may find that Medicare will deny the bill for the two procedures not being simultaneous. There have also been cases of denial where the evidence has shown that the oncologist directing the cancer treatment was not the person directing the dental care.

If your oncologist prescribes treatment that necessitates dental work as part of that treatment plan, there are some important steps that you can take up front to help ensure the best chance of getting your dental work covered by Medicare.

1) Ask the physician who is directing your cancer care to incorporate a dental care plan into the primary cancer treatment plan. Your doctor can actually prescribe and/or indirectly supervise the dental services related to your cancer treatment, and can specifically document any needs related to nutrition for your recovery.

2) Don't be discouraged if your first or second level of appeal is denied. This is not uncommon. However, later when you have to justify your coverage request, you may be able to show that the dental care you received was not routine and meets the standards for being an integral part of your covered treatment for cancer. Making your case to a human being is sometimes easier than appealing on paper.

3) Keep a private dental policy in force. Some claims that are denied under Medicare might well be partially covered under major services in an individual dental insurance policy.

Your insurance agent or broker may provide you with assistance in filing appeals so be sure to check with that person for help.

In summary, we know that there is much to learn about Medicare. Many people may have concerns when transitioning to Medicare for the first time. The good news is that the coverage is pretty good and there are hundreds of thousands of participating providers to choose from. In addition, many affordable and comprehensive supplemental insurance options are available to you to minimize your financial exposure, even when treating for a major illness like cancer.

Keep in mind also that you are certainly not alone in feeling confused by Medicare, and there are many professionals and information sources to help you out there. Knowledge is power, so we encourage you to check out www.medicare.gov for further information about Medicare itself, and for more reading about supplemental insurance options, you are welcome to visit www.boomerbenefits.com where we have detailed descriptions of the options we've discussed in this article. Our best to you!

Editors Note: Danielle Kunkle is a founding partner of Boomer Benefits, a family-owned agency specializing in Medicare-related insurance products since 2005, serving Medigap policyholders in over 40 states. An expert in the Medicare-sector of the health insurance industry, Danielle has spoken about Medicare and healthcare reform for employer groups, agent chapters, hospitals and community organizations in Texas. Her articles about Medicare and Healthcare reform have been featured in Benefits Selling Magazine, where she has also been spotlighted. An active member of the National Association of Health Underwriters, Danielle is a past president of the Fort Worth chapter, has served on the board of directors for the past 6 years and is a recipient of the chapters Outstanding Member of the Year award. She is also a Medicare Supplement

Patience + Persistence = Payment
Credit to Nancy E. Leupold, Survivor, President and Founder

Accredited Advisor through the National Association of Medicare Supplement Advisors, and a is a summa cum laude graduate of Texas Christian University.

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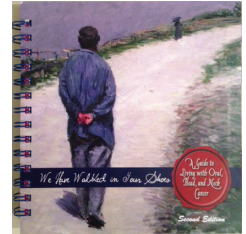
Calling All SPOHNC Chapter Facilitators and Healthcare Professionals!!

*We Have Walked In Your Shoes: A Guide to Living With Oral, Head and Neck Cancer
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Patients, caregivers and healthcare professionals have welcomed SPOHNC's new edition of *We Have Walked in Your Shoes: A Guide to Living with Oral, Head and Neck Cancer – Second Edition*. Many facilitators and healthcare professionals know the value of this book for newly diagnosed patients. Have your Head and Neck Department place a bulk order to save money.

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Order your books today! *We Have Walked In Your Shoes* contains the basics about the symptoms and diagnosis of head and neck cancer, types of treatment and common side effects. It also offers a section to list your healthcare team, a personal calendar and journal, diet and nutrition information, and a list of resources. It is beautifully illustrated with impressionistic paintings of the 1800's.

In Memoriam

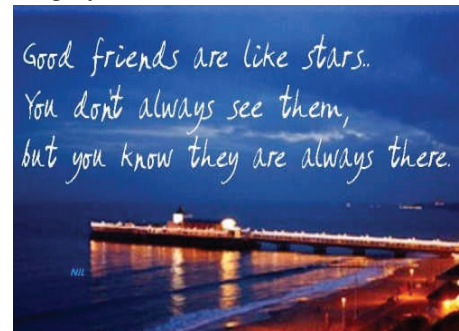


SPOHNC was very sad to learn of the passing of Janet Wilder, of San Benito, Texas. Janet was an extremely supportive volunteer for SPOHNC's National Survivor Volunteer Network, helping newly diagnosed patients since 2007. She also shared her story in the May 2008 issue of "News from SPOHNC", where she inspired readers by telling of her cancer journey, her recovery and her involvement as a very talented actress in community theatre. Janet was an active, vibrant woman, who took care of herself and her body, mind and soul through regular trips to the gym, yoga classes, water aerobics and pilates.

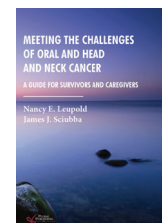
Janet loved to travel. She attended SPOHNC's 20th Anniversary Conference

and Celebration of Life in May of 2012, where we met the woman who would tell us that she felt that her story was "no big deal." Janet told us that what she had been through was "nothing compared to what some others have endured." At the Anniversary, Janet became friendly with survivor, Patrick, and Pam Dockweiler, who shared the news of her passing with SPOHNC. Pam said of the Saturday night Celebration of Life "After the dinner we actually met her dancing... what a lovely woman. After the weekend we kept in touch on facebook."

SPOHNC is grateful to Janet for all of the support she gave to those who were traveling their own cancer journey. We will keep Janet and her family and friends in our prayers.



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How Important is Support?

Gene Monahan, retired New York Yankees athletic trainer, and survivor and speaker at SPOHNC's 20th Anniversary Conference and Celebration of Life, shares his thoughts...

For all the great folks who are directly affected and/or are a supporter of SPOHNC, please know that in my heart, I am with you, now and for always. There is no definable description of what support and it's importance has on "our population," - patients of oral, head and neck cancer.

Personally, at the early stages of diagnosis, plans, initial treatment(s), and long-term care, I grew and learned from my cancer colleagues - those who traveled the same journey I



was about to take. From the onset, the frank honesty of the aspects of this journey, although frightening and impacting, pointed me in a totally positive direction to understand and grasp the mindset of my surgeon. "We only play to win" is what I learned from him, and those words of direct support will forever remain in my daily thoughts as well as when I am supporting others.

April 19th of this year marks my fifth complete year of post-radiation and post surgery. To celebrate is mighty great! But the future remains a journey and assisting my brothers and sisters who are on their own journey now, remains totally paramount! Reaching out to support those who need it, means the world to not only the patient but the supporters as well.

Those of us who will always remain on this journey experience regular and normal side affects that concern us. Every stiff neck, every sore throat, every respiratory issue, are ALL indicators that present moments of anxiety and fear. And so, this is why support is so vitally important. Helping SPOHNC to support newly diagnosed patients just beginning their journey is a crucial need that we all must help to fill. Your donations to SPOHNC will help to support the many resources and programs they offer.

I've spent my entire adult professional life dedicated to professional baseball players, with the world's greatest franchise. And, I am here to tell you, communication is everything. A team that communicates..... wins. We MUST all support, actively and from the depths of our hearts.

A truly great American, Maya Angelou, once told us all, "People will not remember what you said to them, or what you did to them. But, they will definitely remember how you made them feel."

HEAD AND NECK CANCER NEWS

Head and neck cancers in young adults are more likely to be a result of inherited factors

An article published online today in the *International Journal of Epidemiology* pools data from 25 case-control studies and conducts separate analyses to show that head and neck cancers (HNC) in young adults are more likely to be as a result of inherited factors, rather than lifestyle factors such as smoking or drinking alcohol.

Approximately 550,000 new cases of HNC are diagnosed worldwide annually, with an increased incidence in young adults (YA) also being reported. In particular, reports indicate an increase in tumours affecting the tongue and oropharynx among young adults in Europe, the United States, India, and China.

Dr. Tatiana Natasha Toporcov and colleagues pooled data from 25 studies from the International Head and Neck Cancer Epidemiology (INHANCE) consortium to compare the role of major risk factors and family history in HNC for YA (45 years of age or younger) and older adults (over 45 years of age). Participants were surveyed about their history of cigarette smoking, alcohol drinking, and diet, as well as family

history of cancer. In total, there were 2,010 cases and 4,042 controls in YA, and 17,700 cases and 22,704 controls in older adults. The attributable fraction (an estimate of the proportion of cases which could be avoided if the exposures were eliminated) for smoking on the risk of HNC was 20% in young women, 49% in older women, 46% in young men, and 64% in older men. The attributable fraction for drinking alcohol on the risk of HNC was 5% in young women, 20% in older women, 22% in young men, and 50% in older men. Eating a diet rich in fruits and vegetables was shown to be inversely associated with the risk of HNC in both age groups.

Family history of any type of cancer was directly associated with HNC risk only among the older group, but a family history of early-onset cancer was associated with HNC risk only in YA. The attributable fraction for family history of early onset cancer on the risk of HNC was 23% in young adults and 2% in older adults. Dr Toporcov says: "To our knowledge, this is the largest study to evaluate the role of the major risk factors for HNC in

young adults as well as to compare risks in younger and older patients. The large sample size allowed us to elucidate any differences in the role of risk factors in HNC in YA according to age group, sex and cancer sub sites."

"Although they were less likely to be drinkers and/or smokers, alcohol consumption was a risk factor for HNC in YA. However, a stronger association with heavy drinking was observed for the older group. Our results also indicate that the inverse association with fruit and vegetable intake is similar among young and older populations. YA were more likely to have been diagnosed with oral and oropharynx cancer than older adults. Also, early onset cancer in the family was associated with HNC risk only among YA."

"Our results support public health efforts to decrease exposure to major risk factors for HNC in the population regardless of age. However, investigations of the role of other risk factors, such as human papilloma virus and inherited characteristics, on HNC in the younger age group are warranted."

Visit the SPOHNC website at www.spo-hnc.org

NATIONAL SURVIVOR VOLUNTEER NETWORK HIGHLIGHT

SPOHNC's National Volunteer Survivor Network began in 2004. Eleven years later, SPOHNC is proud to say that we have more than 200 volunteers in the program, and have made more than 1,200 matches since its inception. Newly diagnosed patients and volunteers have found the program to be a wonderful addition to the programs of support that SPOHNC has offered since the beginning. Patients find hope and encouragement when they are able to connect, one to one, with someone who understands what they are going through. Volunteers feel a deep sense of gratitude that their experiences and all they have been through can be used in such a positive way.

Our National Survivor Volunteer Network volunteers are truly special people. They give of themselves, every day, to help improve the lives of those who have been affected by the diagnosis and treatment of oral, head and neck cancer. One such volunteer is SPOHNC's good friend, PJ Jordan, of



Richmond, VA.

PJ's husband, Mel, was diagnosed in 2002 with nasal cancer. Mel's treatment consisted of a total rhinectomy, as well as radiation. PJ has shared their story in a previous issue of "News from SPOHNC." Mel had a prosthetic nose constructed for him, which he wears today. PJ and Mel have been dedicated, since Mel's recovery, to helping others who may travel a similar journey. They are kind, caring, and committed to assisting those who seek hope and encouragement throughout their cancer journey.

PJ's interest in photography keeps many survivors inspired, through her pictures that she posts each day on facebook, and on her blog as well. SPOHNC recently came across this beautiful, peaceful photo, taken by PJ. We asked her permission to share it with you... and here is her reply to our request...

"The picture...you may use in any way you wish and say anything you like. Isn't that a great place? People open up their places to let us take pictures for cancer patients and it's overwhelming the reception we get. We



have been invited to gardens, horse farms, to eat dinner, have some tea, you name it. Mel is so well known in his mask in our little town that everyone seems to love and respect him. He calls it his "chick magnet" since he gets so many hugs from the ladies. Truth be told, most of them find him approachable and want to chat about their cancer or their husband's cancer. Oh my, yes, I'm honored and you are welcome to use any photos anytime...that's who they are taken for, cancer patients."

XX OOO - Thanks, PJ

Mel affectionately refers to their trips around the area as "Driving Miss Daisy." There are many beautiful places around Richmond, and PJ manages to capture the most beautiful sights in nature, architecture, and anything else you can think of. She and Mel enjoy sharing their cancer journey, as well as their daily journey, which is captured through so many of her beautiful photographs. Thank you, PJ, for sharing your world with SPOHNC's readers, and with those who have been affected by a cancer journey of their own.

SURVIVOR NEWS

Recently, SPOHNC Syosset, NY Chapter attendee Frank Marcovitz and his wife, Carrie, visited the Hofstra University, graduate Speech-Language Pathology class. Frank affectionately referred to his presentation in an e-mail to SPOHNC, with this photo, where he said "Once again, I've given my body to science and the female gender!!" This was the second time Carrie and Frank have made a presentation to this class.

Barbra Lederer, M.S. - CCC/SLP, class instructor, shared these thoughts with SPOHNC - "I had a classroom filled with graduate students in Speech-Language



Pathology who were waiting anxiously for our speaker to begin. Many of the students had studied the science of Laryngectomy but had never seen or interacted with someone who actually experienced removal of their larynx... and then they met Frank Marcovitz who spoke candidly about his experience, frustrations, highlights and

his zest for life. He encouraged any and all questions and we all felt his desire to expand our knowledge on this subject. He was so genuine and enthusiastic as he told us of his life today." Barbra added "Frank is a compassionate and passionate man who

taught all of us many lessons in life. I will continue to reach out to him in the semesters to come to help educate future Speech-Language Pathologists."

The SPOHNC national office affectionately refers to Frank as "Our Iron Man." You may remember his story from a few years ago, where he shared his cancer journey in an issue of "News from SPOHNC." Frank definitely does have a unstoppable zest for life, and with Spring upon us, if you're here on Long Island, you never know when you might see him on a volleyball court or a long distance bike ride with his club - that is if you don't catch him on a dance floor!

Thank you Frank and Carrie, for sharing your inspiring story with students who undoubtedly learned a great deal from you both. Keep up the great work you do!

SUMMER BRUNCH

from *Eat Well Stay Nourished A Recipe and Resource Guide for Coping with Eating Challenges - Volume 2*

Zucchini Squares

- 4 c. grated zucchini
- 1 c. ground flax seed or bread crumbs
- 1 c. parmesan cheese
- ½ c. canola oil
- 4 eggs, beaten
- 1 sweet onion, chopped
- 2 cloves garlic, chopped
- 1 tsp. bouillon pepper, to taste



In a large bowl, mix all ingredients together. Spread in a greased rectangular pan. Bake approximately 30 minutes at 350 degrees, until middle is solid. When cool, cut into 2 x 2 inch squares. Serves 18.

~ Valerie Targia, CA

Vanilla Custard with Fresh Strawberries

- 2 c. milk
- 5 large egg yolks
- 5 oz. sugar
- 1 ½ oz cornstarch
- 1 tsp vanilla
- fresh strawberries



Scald milk with vanilla. In separate saucepan, mix egg yolks, sugar and cornstarch. Whisk until pale yellow, thick and smooth. Slowly add hot milk to egg mixture, whisking constantly. Return mixture to stove and cook over medium heat until mixture thickens and smoothes, whisking constantly. Cool quickly; sprinkle a little sugar and cover with plastic wrap to prevent a crust from forming. Chill in refrigerator. Serve with fresh strawberries, hulled and halved. Serves 4.

~ Hannah Swenson, NY

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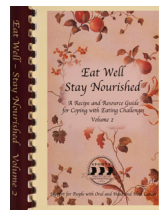
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SUMMERTIME and SPOHNC



Although our newsletter takes a summer break, SPOHNC is still here to help!

SPOHNC continues to provide support year round to those who have been affected by the diagnosis and treatment of oral, head and neck cancer. Our Chapters are meeting and growing, and our NSVN match program continues to offer help and hope to newly diagnosed patients and caregivers. We will continue to keep in touch with you through our e-mail blasts and facebook. Please call us when you need us – at 1-800-377-0928, or e-mail us at info@spohnc.org.

Connect with SPOHNC's "group" on Facebook

TIME FOR SHARING...Getting Cancer

A couple of years ago when I was working in Algeria, Africa, I noticed that a gland below my left ear was sort of sore. I thought it was allergies or something like that. I went to our on site medical facility and they wrote me a prescription for some medicine. I took that for a week and then waited another week...nothing changed. I



went back and they gave me something to take for an infection. Still nothing changed after another week. I noticed that when I was walking up hill I became out of breath pretty fast. That was unusual because I was in good shape.

I emailed my wife, Karen, and told her to make me a doctor's appointment for when I came home in a couple weeks. My second day home, I saw my doctor. He said "you have something going on in there and I will recommend you to a specialist." The next week we went to the church where we were married, and I talked to the pastors. I told them that I thought it was something serious. They prayed that the Lord would provide me with the best doctor and medical treatment and that I would once again be healthy.

I saw my new doctor and he scheduled some necessary tests. They stuck a big needle in the now swollen lump on my neck to get a sample of it. Boy did that hurt!

A few days later, the doctor said they could not tell enough from that test and he wanted to operate and take a piece of the lump out for testing - so we set that up and he took his sample. The next day the phone rang and he said to come in to see him, so in we went. He said, "Your sample results came back positive for having cancer. We need to operate as soon as possible." I said, "So what are you doing in the morning?" He said, "We are operating." He

made arrangements for me at the hospital and I checked in the next morning early. He operated and it took seven and a half hours.

The tumor was in the muscle that runs down the side of your neck and off onto the top of your shoulder. The tumor had blocked off the vein that returns blood from the left side of your brain to your heart. Thank God that we have a bypass built in. It was working great. The tumor had started blocking off the artery that supplies blood to the left side of the brain. He was able to remove the tumor from it and flow was back to normal. The nerves that operate my voice box, tongue and jaw went through the tumor. He separated them from it. While he was in there he took samples of my lymph nodes to see if they had any sign of cancer in them.

The next morning when I was awake, he came in to see me. He said "How are you doing?" I said, "Pretty good, I think." He got this big smile on his face. Then he said, "Can you touch the top of your head with your left hand?" I lifted my hand and touched the top of my head. He was thrilled and told me that was fantastic - then he told me about the operation. He said he had to remove the muscle up the side of my neck and didn't know if I would be able to lift my arm. He said he was not sure if my voice box would operate along with my tongue and jaw. Everything went better than he thought it would. I told him that I was going to be his poster boy for these kinds of operations. He said he wouldn't doubt it a bit.

They did a pet scan on me to see if I had cancer anyplace else. That came back negative. A month later I started my radiation treatment to kill off any particles that might have been missed in the operation. They made a plastic mask that fit exactly to my face. This mask would snap to the table that I had to lay on to get my radiation treatment. This was to be sure that my head was in the same place each time. They even put a small tattoo dot on my chest so I would be lined up on the table exactly the same each time. I went five days a week for eight weeks.

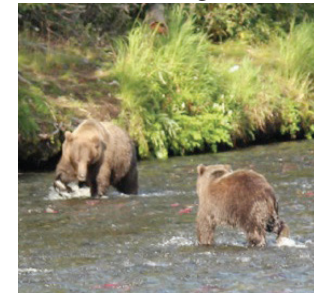
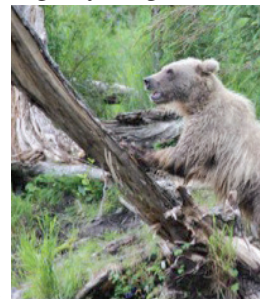
I lost weight, going from 250 lbs. to 170 lbs. during this time. The treatment

stopped the flow of saliva and my sense of taste went away. All, that is, but salt. Everything tasted like salt. It was hard to drink coffee, so I gave it up. Water even tasted like salt water. I could hardly get it down. I got dehydrated and they gave me an IV to get my liquid back up. I told my wife to get some beef bullion cubes and dissolve 1/2 of one in a tall glass of water. That was supposed to be salty. Ah, I could drink again. It was all mental so I just fooled myself. Then I had to wait another month and then they could do another body PET scan to see if cancer showed up anyplace. I was clear, no sign of cancer.

My doctor gave me a work release and I went back to North Africa and finished the job there. Some of the guys asked me why I came back? I said it was for my head. I needed to know I was back to normal. Sure I'm not like I was before but, my spirit is stronger than ever. Life is change, from the first breath to the last breath. It is up to us to make the most of it as we go along.

I see my doctor every time I go home so he can check me out. He said I'm doing great. My saliva is back but it is still a little thicker than normal. My sense of taste is back. Some things don't taste as good as I remember them tasting. My weight is back up to 220 lbs.

I keep a positive outlook on life and enjoy it each day. I'm creative through photography and art because it keeps your mind in a positive mode, when I'm creating something. I'm working



in Alaska now on a power plant. In my spare time, I have written two children's books about brown bears that I have photographed here. This one is "A Brown Bear's Story" the second one is "Mother Bear Teaching Cubs to Fish." I put them
continued on page 10

continued from page 9



both into one book. "Brown Bears of the Alaskan, Russian River". The book is on Amazon & Kindle Books now. I have also produced several pieces of art from driftwood that I collected along Kenai Lake. I give the artwork away

to people that I work with or send them to family. Here's an owl I sent to my grandson for his 22nd birthday. The walrus went to a friend from NY. I'm six years free from cancer now as of 9-26-2014. Life is good!



Richard V. Shaffer
~ richardvshaffer@yahoo.com



Happy Spring! Undoubtedly, we're all glad to put this Winter behind us and move ahead. Here at SPOHNC, we are already looking ahead, to future issues of "News from SPOHNC." The newsletter is one of the many benefits of SPOHNC membership. The **Sharing Story** is one of the most popular sections of the newsletter. The stories share the personal journeys of those who have been affected by oral, head and neck cancer, from diagnosis, to treatment and beyond. Stories can be shared by survivors, caregivers or even siblings or family members of those who have been affected by the diagnosis of oral, head and neck cancer. Many of our readers are newly diagnosed patients who need to see that there

is hope - and the sharing stories provide that hope.

SPOHNC is currently seeking additional Sharing Stories for upcoming issues of the newsletter. We usually ask for about 2,000 words, with a photo, so that our readers can get to know you, the author, in a more personal way.

Many of you are reluctant to write because you don't see yourself as a writer. SPOHNC is happy to help anyone who is interested in sharing their head and neck cancer journey in a future issue of "News from SPOHNC." We can help with editing, suggestions and grammar as well if needed. The point is that the story comes from your heart.

Please consider sharing your story in a future issue of "News from SPOHNC." Summer is the perfect time to write your story, and you can send it to us at any time. Contact Chris at 1-800-377-0928, x4 for details, or e-mail your story to info@spohnc.org, or c.leonardis@spohnc.org. Inspire a newly diagnosed patient by sending us your story today.

HEAD AND NECK CANCER NEWS

HPV Vaccine Can Protect Previously Exposed Patients

April 22, 2015 - Vaccinating women between the ages of 18 and 25 against the human papillomavirus (HPV) resulted in protection at the three known sites of viral entry. The HPV 16/18 vaccine protected women from cervical, anal, and oral HPV infections that can lead to cancer. Women who were previously exposed to HPV were also partly protected from new HPV infections.

In the study, women vaccinated with the HPV 16/18 vaccine were significantly less likely to be infected at two or more anatomic sites (7%) compared with women who received a control vaccine (30%) ($P < .01$).

These results were presented at a press briefing at the American Association for Cancer Research (AACR) Annual Meeting, held April 18 to 22 in Philadelphia, by study author Daniel C. Beachler, PhD, a postdoctoral fellow in the infections and immunoepidemiology branch of the National Cancer Institute.

According to Beachler and his co-authors, this study is the first to show a multi-site vaccine efficacy. "Individuals can acquire HPV infections in the epithelium of their cervical, anal, and oral sites, and occasionally these infections lead to cancer," Beachler told *Cancer Network*.

"The HPV vaccines are highly effective at preventing HPV. In the U.S., persistent infection with HPV is known to cause about 25,000 new cases of cancer each year at the cervical, anal, and oropharyngeal sites," said Beachler. "Worldwide cervical cancer is one of the leading causes of cancer death in women. These vaccines have the potential to greatly reduce this cancer burden in the future."

The researchers analyzed 4,186 women who took part in the randomized, controlled Costa Rica Vaccine Trial. The participants were assigned to vaccination with Cervarix, the HPV 16/18 vaccine, or a control vaccine, and had cervical samples taken annually post-vaccination and oral and anal samples taken every 4 years.

Beachler and colleagues assessed how well vaccination protected against infection at all three viral entry sites. Efficacy was 83% among women with no prior history of HPV exposure or infection and 58% among women who had a history of HPV exposure before vaccination. Efficacy was not significant (25%) among women who had an active cervical HPV 16/18 infection at vaccination. Overall, the multi-site vaccine efficacy was 65% and increased to 91% for protection of at least two of the three viral sites of entry.

While the vaccine is not a therapy for ongoing HPV infection, the study shows that in women who have had an HPV infection, the vaccine can prevent subsequent infections at other sites of viral entry.

HPV vaccination is currently recommended in the United States for girls and boys aged 11 to 12 years and through the age of 26. Women up to the age of 26 and men up to the age of 21 should also be vaccinated if they had not received the full three-dose vaccine as preteens. Still, only about 50% of women younger than age 18 are receiving the HPV vaccine in the United States.

"This research supports current U.S. guidelines for HPV vaccination from the Centers for Disease Control," said Beachler. "This study provides further evidence that most females vaccinated between the ages of 18 to 25 can receive protection at one or more anatomic sites from the HPV vaccine. This is important given that only about half of U.S. females under 18 have been HPV vaccinated."

If these study results are confirmed, then women who have been previously exposed to either HPV 16 or 18 should consider receiving the HPV vaccination, according to the study authors.

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See you in September!

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