Concerns with changes in body image are very common in patients with head and neck cancer. From my research I have shown that the vast majority of head and neck patients acknowledge experiencing concerns or embarrassment about bodily changes resulting from cancer and its treatment at some point following diagnosis.

Body image is not just about physical appearance – it includes the way you perceive, think, and feel about your entire body and the way it functions. There are many different types of bodily changes a person with head and neck cancer may experience that can cause embarrassment and distress. Among the most common complaints and concerns are scarring/disfigurement, altered speech, difficulties eating/swallowing, loss of teeth, loss of hair, drooling, dry mouth, weight loss, weight gain, swelling, skin discoloration, and impaired sexuality. Most patients experience more than one type of body image complaint or concern.

Body image concerns can arise at any point following diagnosis and treatment. For some patients, these concerns and difficulties arise at the moment of diagnosis. A lot of individuals struggle greatly with anxiety about how upcoming treatment is going to alter their appearance or functioning. Others begin to struggle with disfigurement and functional loss while undergoing active treatment. Yet some deal relatively well with body image changes throughout treatment – but begin to experience marked distress or anxiety about disfigurement and functional loss as treatment nears completion. Many of those who experience later onset of body image distress become truly shocked and dismayed that they are having trouble coping since they feel they did so well during treatment.

The next big question is – how do body image concerns ultimately affect people’s lives? This can vary a lot from patient to patient. A big part of the problem is that most people tend to feel ashamed and guilty for having these concerns. They don’t understand why they are so concerned or bothered by appearance changes or functional difficulties, especially if they have a good prognosis for their treatment. They are reluctant to talk with others about these difficulties or seek help for fear of being seen as “vain”. This guilt and embarrassment can lead to social isolation and withdrawal. Some patients experience severe levels of social isolation. They may have difficulties returning to work or resuming other activities they once enjoyed even though they are physically able to do so. Much of this has to do with feeling self-conscious about being in public or in social situations.

Below are some basic tips that may help you or a loved one struggling with body image changes resulting from cancer and its treatment:

- Acknowledge the way you truly feel about changes to your appearance or functioning. It is OK to cry, to be worried, to be upset – in fact, these feelings are entirely normal. Try not to downplay the way this is truly affecting you. Ignoring, or trying to hide these difficult feelings may strengthen them. Facing and working on them may diminish the fear and allow you to move forward.
- Talk about your feelings and experiences with people you trust. Help them understand what you are going through and allow them to support you. Let others know that just by listening to you they can be helpful.
- You can also take some time to write down your thoughts and feelings in a journal. This will give you the opportunity to privately reflect on your experiences and provide a place for you to express some strong emotions.
- Resist the urge to withdraw. Withdrawing from normal activities or your social group is a natural reaction, but not the healthiest response. If your body image concerns are keeping you from doing things you want to do or significantly interfering with your daily life, you may want to talk to a mental health professional.
- Take some time to reflect upon aspects of your appearance you like and enjoy. Regularly plan activities that make your body feel good and enhance physical features you enjoy or want to celebrate. For example, take a warm bath, ask for a backrub or foot massage, wear clothing that feels good on your skin, have a manicure, start a new gardening project, or do any type of physical activity (walking, yoga, stretching, swimming, dance, sports).

During the last several years, I have had the honor and pleasure
BODY IMAGES continued from page 1

of working with more than 200 patients and their families. These individuals share with me their struggles and successes on the road to achieving greater body image acceptance. Body image acceptance does NOT mean liking everything about your body or being wholly satisfied with the way you look. It involves an awareness of the things you like and dislike about your body and a willingness to tolerate and accept yourself “as is”.

Although the patients I work with have many different tumor sites, different treatment regimens, and different types of bodily changes they undergo – there are many similar themes and issues that arise during therapy and after. Five of the most frequent topics of discussion and some thoughts on how to best deal with these difficulties are listed below.

Viewing Yourself For the First Time after Surgery

It is normal to show a reluctance to view yourself in the mirror for the first time after surgery. First, it is important to talk with members of your healthcare team to have some understanding of what to expect of your appearance. You may also benefit from having others (friends/family members) describe your appearance changes to you in an objective manner. Statements such as “you look good” or “it looks a lot better than I thought it would” are not helpful in describing the actual appearance changes. Try and view your appearance as soon as you feel mentally ready and do this prior to leaving the hospital. You may want to have a nurse or trusted friend with you to help discuss your reaction or you may prefer to do this alone.

There are several reasons it is helpful to view yourself early in the recovery process. In most cases, you will experience the most drastic change to your appearance in the first few days after surgery. By viewing yourself in these moments, it will give you a better understanding of your starting point for recovery and allow you to more fully appreciate improvements in your appearance that occur over time. Viewing your appearance is an important step in your recovery as this allows you to begin the process of adapting to your changed body image. Each time you view your appearance it should get a bit easier, though you do want to be careful to avoid obsessively viewing your appearance.

Be prepared for some change when you view yourself for the first time, and there is a possibility that your appearance may be shocking to you. It is very likely that the way you look is different from how you were picturing it in your mind. Allow yourself time to absorb these changes, and remind yourself that time and support from others will help you adjust.

Reactions from Grandchildren and Children

I truly understand why people get so worried and upset about the way their young children or grandchildren will react upon seeing them for the first time when there has been some sort of appearance change. I want to reassure you that young children are often much more resilient and adapt better to difficult situations than we give them credit for. Children are mostly concerned about whether you are in pain or suffering rather than what you look like. It is amazing to me just how often these dreaded situations go well and patients feel comforted and reassured by youngsters.

BODY IMAGES continued on page 3
BODY IMAGES from page 2

There are a few things you can do to prepare children for this first encounter. Speak with them by phone or email and reassure them if you are feeling well. Have another adult objectively describe what is different about your appearance. For very young children you can make this more concrete by showing them on a doll where bandages are placed or pointing to specific areas on the face and describing how they are different. Use Skype or other video conferencing to give them a glimpse of your appearance prior to an initial face to face encounter. Allow them to ask you questions.

Dealing with Comments from Friends and Family

Many people tell me that well-meaning comments about how “good” they look or how well they seem to be coping can be very difficult to hear at times. This is especially true when they are struggling with feeling self-conscious about their appearance or experiencing difficulties coping with functional loss. If these comments are particularly bothersome to you, it is important for you to speak up and let people know. Explain to them that you are really struggling right now and that while you understand people mean well – this is not at all helpful to hear. One of my patients directed her family and friends that she would feel better supported by statements such as “It is so good to see you” or “I’m so happy to be spending time with you”.

The reason these comments are so difficult to hear is because they are at odds with your own personal body image. It is important to keep in mind that body image is completely personal and subjective. This means it has nothing to do with what others see or perceive – it is entirely about how you perceive your body. This helps to explain why your spouse and friends can truly think you look “good” whereas you may think you look “horrible”. It is important to be able to take some of these comments at face-value. Many people truly mean it when they tell you how good you look – whereas you are too quick to discount it and think there is no way they could possibly mean it. What if they really do feel that way? Have you thought about that?

Facing the Public; Coping with Stares

This concern is shared by people with appearance changes as well as those with functional loss involving speech and/or swallowing. Here is the bottom line: if you have an obvious appearance change (such as loss of an eye, significant scarring, swelling, skin discoloration) – you will inevitably have to deal with stares and double-takes. In most cases, this reaction is due to curiosity or recognizing in a glimpse that there is something unique and different about you, something a stranger is not expecting to see. It is not something malicious or meant to be spiteful. It is an involuntary reaction. Of course there is the possibility that there will be unwanted comments that accompany these stares and double-takes but this is much more likely to be an exception and not the rule.

How should you go about dealing with the reactions of others? In most cases, I would recommend ignoring the reaction completely or making a simple assertive statement to let the other person know you want them to stop staring at you. You could even consider simply glaring back at them which in most cases will get the other person to look away. Alternatively you could choose to engage the person in conversation or even smile back. One patient told me she was in line at Disneyworld and there was a child staring at her. She felt so self-conscious and uncomfortable and then decided to try and smile at the girl. The girl instantly smiled back and the awkward situation was resolved.

Many people misinterpret the stares of others; that the stares of the observer are a sign of being horrified at your appearance or ill at ease with your speech impairment, drooling, or other changes. These are assumptions that you are making. In truth, you cannot read people’s minds so you don’t know what they are actually thinking. There is an endless possibility of what thoughts cross people’s mind when they come into contact with you. When it comes to strangers, it is also important to remind yourself that these are people you most likely will not interact with again in the future.

Social Situations and Events

This is a very broad category because it includes small intimate gatherings with friends or family, large social gatherings, and work settings. If you have been avoiding such situations, pick and choose settings where you feel the most comfortable and gradually challenge yourself to reintroduce more activities. Use nonverbal communication skills to help you communicate with more confidence. Only discuss topics that you feel comfortable with when it comes to your cancer and its treatment. You can direct the conversation away from yourself by asking something about the other person or discussing a shared interest with others. Remember to stop making assumptions about what others are thinking or how they feel about you.

Finally, I would like to focus a bit more on the work I do with those who have experienced functional loss involving speech and/or swallowing. Many individuals with speech impairment experience particular distress with communicating by phone. Resumption of telephone use can be empowering and is something I encourage and assist patients with. In most cases patients are more easily understood by others than they realize. There is no need to completely eliminate this source of social connection even though there are other avenues available (text, email).

For those struggling with functional limitations of eating, mealtime can obviously become a source of stress. Don’t assume that your inability to eat or reduced ability to eat makes others uncomfortable. You may be surprised to learn that your absence is more concerning or bothersome. Even if others feel slightly uncomfortable around you – this is no reason to isolate yourself. Over time your friends and family will get used to these changes if you give them and yourself the opportunity.

Additional resources for coping with body image changes can be found on the Changing Faces Organization website, www.changingfaces.org.uk. Changing Faces is a charity organization in the UK that supports people who have disfigurement of the face or body from any cause.

Editor’s Note: Michelle Cororve Fingeret, PhD, is a clinical psychologist and body image specialist in the Body Image Therapy Program at MD Anderson Cancer Center which was launched in 2008 to help provide support and counseling to patients experiencing distress about changes to their body image. This program is designed to help patients learn new coping strategies for managing body image concerns, to better prepare patients for upcoming body image and appearance-related changes they are about to experience, and to discuss ways to communicate more effectively with people about appearance and body changes they have experienced.

S•P•O•H•N•C

http://www.spohnc.org

E-mail-- info@spohnc.org
A TIME FOR SHARING...The Third Promise

In 2005 I was diagnosed with Stage 4 Squamous Cell Carcinoma, primary site in the right tonsil and metastasized to the lymph glands. My Son Dale made a heavy metal CD which I called my “Kill Cancer Music.” During radiation treatments, the techs would crank it up, and I would dream of better times. Having a “Marquis de Sade mask” of my very own and feeling those nine straps being snapped closed contributed to my already existing claustrophobia.

I was treated at the Dana-Farber Cancer Institute where every staff member exudes warmth, kindness and a hopeful spirit, but even with a top medical team and a loving, supportive family, cancer is not a head cold. Being told that you have cancer is terrifying. Thankfully, being cared for at one of the top cancer medical facilities in the world was, and is, a fear-reducing gift.

During my radiation treatment, I envisioned cancer cells being burned to a crisp and running out of my body, screaming - a picture I enjoyed. It also helped that I made myself three promises, since making promises means one expects to be around to fulfill them. Two of the promises are sound and one is silly, but all three helped me to look forward with hope for myself, and for other Head & Neck patients. I believe we are all in this cancer war together and when we help each other, we help ourselves.

The first promise was to ask my oncologist to let me know when I could volunteer. He did, and so for nearly five years now, I have gladly traveled the 130 miles round trip from central MA to Boston to volunteer every Wednesday on the infusion floors. My volunteer partner Marlene and I listen to and talk with patients from all over the world, who are dealing with all sorts of cancers. The experience is incredible, the patients are brave and the moments together are of great value to each of us. I am honored to have this opportunity.

The second promise was frivolous and still brings me smiles. The sound of the radiation machine while in that cold darkened room made me long for the warmth of the sun. I decided that from then on I would only use yellow pocketbooks and purses - that way, no matter how badly I felt or how much pain I was experiencing, I could look at a sunshine bag and smile. I gave away all the pocketbooks I owned and got a yellow shoulder bag. Between family and friends the collection of yellow pocketbooks and purses has grown, so I now have enough to share with cancer patients and survivors when it seems as if they could use a bit of sunshine in their lives. When those moments happen, we all smile.

If I was alive in five years, my third promise was to host a gala fundraising event with my husband Tom “Satch” Sanders, a prostate cancer survivor.

It’s 2011 and I am a survivor because of research and an experimental protocol. Satch and I are both so happy to be alive and feel as good as we do and so, on April 15, 2011 we are paying our gratitude forward by hosting the Gin and “Satch” Sanders Gala Sneaker Ball to benefit Dana-Farber Cancer Institute’s Head & Neck Cancer Research Programs.

The Renaissance Boston Waterfront Hotel will be the event location. Guests will enjoy a Cocktail Hour, Silent Auction, Dinner, Awards Ceremony and Dancing to a live band. The attire is black tie (optional), fancy dresses or gowns and of course, snazzy sneakers. (for which we’ll give prizes). We chose the theme because Boston is such a sports-crazy town and because Satch played on eight world championship basketball teams. Satch is a Boston Celtic Legend and has access to many former and current Boston Celtics team members. We are so fortunate to have their support.

The Awards Selection Committee has announced the three recipients for the First Annual Head & Neck Cancer Hall of Fame Awards. In future years, the individual awards will be named after these honorees.

The recipient of the Physician of Excellence Award is Marshall Posner, MD, the Medical Director of the Head and Neck Oncology Center at the Mount Sinai Medical Center and Professor of Medicine at Mount Sinai Medical School. Dr. Posner was formerly Medical Director at Dana-Farber Cancer Institute Head and Neck Oncology. He has published over 190 peer-reviewed basic laboratory and clinical studies, as well as multiple reviews and abstracts. Dr. Posner has been the principal investigator on numerous clinical and translational research trials and has a major interest in the immunobiology and the therapeutics of Human Papilloma Virus and oropharynx cancer.

We are honored to present the Head & Neck Cancer Hall of Fame Patient of Achievement Award to Ms. Nancy E. Leupold. When asked for a bio, this highly accomplished woman provided us with a humble reply that in no way covers all her many accomplishments. Ms. Leupold is President and Founder of Support For People With Oral And Head And Neck Cancer, Inc. (SPOHNC) and is also an oral cancer survivor. She serves and has served on numerous medical boards, committees, and panels related to head and neck cancer research and care. Nancy was awarded the American Head and Neck Society’s prestigious Presidential Citation.
in 2002, in recognition of her outstanding accomplishments toward improving the lives of those affected by oral and head and neck cancer. Her dedication to SPOHNC has led to the development of more than 100 support chapters nationwide, a National Survivor Volunteer Network of more than 175 individuals, three publications, a monthly newsletter, and a newly developed web site. Nancy’s strong commitment to the organization has provided information, support and encouragement to oral and head and neck cancer patients and their families during and beyond their cancer journeys.

The Awards Committee was unanimous in the selection of Warren Perry for the Head & Neck Cancer Hall of Fame Patient of Courage Award. Sadly, Warren will not be here to receive the award, but he was thrilled to be named the honoree and was looking forward to the Gin and “Satch” Sanders Gala Sneaker Ball, to receive the award. Warren Perry was in and out of treatment for twelve years, encompassing a number of rounds of chemotherapy, radiation and many surgeries. Warren finished his battle at the end of January. His wife Jean was with him throughout his various treatment protocols and is now attending to his wake and funeral. Warren was from Maine and was always an optimist. He was brave, funny, helpful, encouraging, charming and funny. He was a wonderful father and grandfather and a truly loving husband. The team of Warren and Jean Perry brought a whole new meaning to the word courage; together they lived it. Warren Perry is already missed. We are pleased that his wife, Jean, has consented to accept the award for his hero.

Our very first award recipients are so worthy of the honors being bestowed upon them at the Gala Sneaker Ball and we are pleased to welcome them to this year’s inaugural event. We hope to grow the event in future years, where we will hear the stories and give the recognition to those in the oral, head and neck cancer community who so deserve it.

The Gala Sneaker Ball is being held in partnership with the Jimmy Fund/Dana-Farber Fundraising department. Sponsorship opportunities are available with various sponsorship benefits, ranging from $10,000 to $40,000. The price per table of 10 is $5,000. Individual, non-corporate tickets are $350. All donations are tax deductible to the fullest extent of the law.

Special guests for the evening include the highly respected and lovely Fox 25 TV news anchor Maria Stephanos. Governor Duval Patrick and Boston Mayor Tom Menino are our Honorary Event Co-Chairs. Our Host Committee includes Boston Celtic Head Coach Glenn “Doc” Rivers, Shaquille O’Neal, former MA Governor Michael Dukakis and many other caring people of note. We wish to thank everyone involved for his or her dedication and commitment to the event.

For additional information about the Gala Sneaker Ball, donating opportunities, award recipients, patient stories and more, visit www.GalaSneakerBall.org. We continue to update our information so visit often.

Satch and I are grateful to the patients and survivors who have shared their stories on our web site. Thank you to SPOHNC and Cancer Compass for steering these wonderful cancer warriors in our direction. Thank you for letting us share this journey as we keep a promise and pay our gratitude forward.

Gin Sanders
Co-Event Director

Eat Well—Stay Nourished: a Recipe and Resource Guide for Coping with Eating Challenges
$20.00
www.spohnc.org
1-800-377-0928

We Have Walked In Your Shoes, A Resource Guide to Living with Oral, Head and Neck Cancer
Visit www.spohnc.org to order.
For large orders, please call 1-800-377-0928

The gift we can offer others is so simple a thing as hope.

~Daniel Berrigan
A Primer on How to Handle Medicare’s Denial of Coverage for Dental Procedures  
By Harry J. Knudsen, JD

INTRODUCTION

Patients who have undergone radiotherapy as a part of treatment for cancer of the head, throat and neck are prone to side effects of radiation which may intensify following the cessation of the radiation. Such patients frequently need dental surgery for which the providers make claims to Medicare.

Most patients know that Medicare does not cover routine dental procedures but may not be aware that some related procedures are covered.

In SPOHNC’s May 2007 newsletter there is an excellent article addressing Medicare coverage of Dental Care following Radiation/Chemotherapy Treatments. I found it helpful in challenging Medicare’s denial of coverage for my wife whose claim was denied for the removal of her left jaw. (Reprints are available from SPOHNC)

Your readers might be interested in our experiences in reviewing Medicare’s denial procedures as a case-study.

HISTORY

Over six years ago (2004), my wife was diagnosed with Stage 4 squamous cell carcinoma at the base of her tongue.

She underwent intensive radiation and simultaneous chemotherapy for six weeks. Although the tumor was destroyed, the side effects of radiation resulted in constriction of her esophagus and later, her trachea. Her nutrition has been administered through an abdominal gastric tube for over six years since she cannot swallow even after twelve dilatations.

Three years ago, she was experiencing a problem with breathing so, after consultation with her ENT surgeon, it was deemed necessary to perform what we hoped would be a temporary tracheostomy. Unfortunately, it is now permanent.

The X-rays and CAT scan indicated that her left jaw bone had been rendered necrotic due to the intense radiation. In medical terms, her treatment entailed a resection of the osteoradiation necrosis associated with the left aspect of the mandible, and the application of an interdental fixation device (a titanium mandibular plate to replace the jaw bone). Shortly thereafter the prosthesis broke through the skin and had to be removed.

The mandibularectomy was performed on October 17, 2007 by her ENT surgeon and an oral surgeon which included the extraction of eight teeth, five of which were from her right jaw to accommodate the placement of the prosthetic jaw.

Medicare and her Medigap insurers paid the ENT surgeon, the anesthesiologist and hospital without a problem, but denied the oral surgeon’s claims for his part of the surgery.

On February 29, 2008, Medicare-Part B denied coverage for the interdental fixation (prosthetic device) repair of tooth socket, and the teeth stating that the “routine care is not covered” but that the claim “was separated for processing”.

Six months later on August 29, 2008 Medicare denied coverage for the dental work.

APPEAL PROCEDURES

STEP ONE:  
Redetermination

Medicare rules require that the beneficiary file a request for a redetermination of the denial within 120 days. (We did within 31 days).

Medicare strictly enforces all time limits which lawyers recognize as a statute of limitations.

STEP TWO:  
Reconsideration

After Medicare again denied the claim on November 18, 2008 and it even claimed it was not appealable, we filed for reconsideration of the denial to be performed by a Qualified Independent Contractor (QIC). (There is a 180 day time limit to file it)

On June 17, 2008, the QIC again denied the claim.

STEP THREE:  
Appeal to Administrative Law Judge (ALJ)

There is a 60 day time limit to appeal to the Administrative Law Judge’s (ALJ) office.

The ALJ office considered the appeal and rendered a prompt decision on July 30, 2009, that it be remanded (returned) to the QIC for reconsideration.

The ALJ called the QIC’s attention to the Medicare Policy Manual and retained jurisdiction.

So, back we went to the QIC.

On June 11, 2010 the QIC again denied the claim. So, we timely re-appealed the denial to the ALJ.

On September 7 the ALJ ruled in our favor on my wife’s claim based on the record we had submitted without conducting a hearing.

Medicare had 60 days to appeal to the Medicare Appeals Council. Since it did not appeal, the decision is now final.

If the ALJ and Medicare Appeals Council had ruled against our appeal, we could have filed suit in Federal Court. (A law suit cannot be filed until the administrative appeals have been exhausted.)

Since the oral surgeon requested payment for his services, we paid him in full. However, Medicare and Medigap carrier must now pay the claim to the oral surgeon, and we will obtain a refund.

COMMENTARY:

Medicare rules on claims are not overly complicated for laymen. Although I am an attorney with over 50 years of experience, I had never previously handled an administrative appeal of a governmental decision.

I found the booklet issued by the US Department of Health and Human Services to be very helpful (CMS Publication No 11353-LE)

The Medicare statute excludes “routine dental procedures” from coverage. However, that term is subject to interpretation. Generally, it excludes services in connection with the care, treatment, filling, filling.
extraction, or replacement of teeth or structures supporting teeth.

Medicare’s Benefit Policy Manual, chapter 15, attempts to further define what constitutes “routine” and it adds a sentence providing that “if an otherwise non-covered procedure is performed by a dentist as incident to and as an integral part of a covered procedure or service performed by the dentist it is covered.” (Emphasis added)

However, there is another exception in the Code of Federal Regulations for inpatient hospital services provided in connection with such dental procedures are required because of (1) The individuals underlying medical condition and clinical status, or (2) The severity of the dental procedures.

The manual gives some examples, one of which is where the extraction of teeth in preparation for radiation is a covered procedure but inexplicably, the extraction of teeth after radiation is not covered.

In my wife’s case due to intense radiation, her left jaw bone became necrotic so it had to be removed. The ENT surgeon requested an oral surgeon to assist in the procedure. The oral surgeon had to remove eight teeth in order to remove her left mandible and prepare for the installation of the prosthesis (interdental device).

The ENT surgeon and oral surgeon worked in tandem employing each of their skills. My wife was hospitalized for three days and sent to a rehabilitation hospital for two weeks.

Even though the oral surgeon submitted a letter-opinion stating that the teeth extractions and placement of the prosthesis were incident to and an integral part of a covered procedure (mandibularectomy), Medicare still denied coverage.

The Administrative Law Judge reviewed the claim based on the evidence we submitted and on September 7, 2010 rendered a “FULLY FAVORABLE DECISION” without a formal hearing.

The “magic” words the oral surgeon or dentist needs to use in submitting the claim is “incident to and an integral part” of a covered procedure.”

Even though the writer is an attorney-at-law, an appeal does not necessarily have to be handled by a professional. It can be submitted and processed by a reasonably intelligent person who has been appointed by the beneficiary in the form prescribed by the Department of Health and Human Services. (You must use the Department’s form to appoint an attorney-in-fact.) Of course an attorney’s assistance would be beneficial. There are several social service agencies who can provide legal assistance without charge for indigents.

While this story is an example of bureaucracy at its worst, we can say that, other than this, we have been well satisfied with Medicare and our Medigap insurer during the past six years.

MY ADVICE:
1. Be sure the dental surgeon uses the “magic words” with the claim.
2. Do not be discouraged by denials.
3. Be sure to act promptly at every stage of an appeal.
4. Thoroughly document your claim with surgical and hospital records.
5. Supplement the documents with letters or statements from the professionals.

(In my wife’s appeal, I obtained two letters from the oral surgeon and also an opinion-letter from another board-certified oral surgeon who reviewed the operative reports by both surgeons who had operated on my wife.)

CONCLUSION
In the event Medicare denies coverage for dental work performed in conjunction with a covered procedure, the appeal process can reverse the denial if you avail yourself of the appeals process and make timely appeals and submit complete documentation.

SPOHNC is happy to report that Meeting the Challenges of Oral and Head and Neck Cancer: A Survivor’s Guide has been very well received. Reviews of this book state it is a “must-read for every patient as well as for those people involved in their care,” Consequently, SPOHNC is preparing to publish a second edition of this book including five additional chapters.

We are asking for your help. If you have found any products that have been very helpful to you, please send us the name of the product and where it can be purchased.
Send your information to: info@spohnc.org or call 800-377-0928
Thank you for your help and support.

Visit SPOHNC on Facebook
What’s so special about April? For some, it’s the promise of showers, leading to May flowers, but for SPOHNC members, friends and family it brings us to Oral and Head and Neck Cancer Awareness Week - April 10th – 16th.

Last year during Awareness Week, several SPOHNC support group chapters across the country hosted their own inaugural Taste Event to bring together survivors, family and caregivers and promote awareness of oral, head and neck cancer. The Taste Events, supporting SPOHNC, invited local chefs, restaurants, bakeries and other culinary establishments to prepare dishes for a buffet style event where guests could sample foods that were appropriate for individuals who may have challenges due to surgery or side effects from cancer treatment. Guests enjoyed the fabulous fare, and found some new ways to prepare dishes that they may not have thought about before.

Plans are already in full swing for this year’s Taste Events, with chapters already committed to participate from Rochester, the Gulf Coast, Chicago, Danvers, MA, Kansas City, Indy North, Stony Brook, Syosset and New Hyde Park. To find out about how to host your own chapter’s Taste Event, read on.

Participating chapters across the country are already conversing with chefs about this year’s culinary creations, designed to delight the palates of guests who attend. Each chapter has its own unique event planned, but we’re certain that all will be treated to an evening where fine food and lively conversation will be on the menu. Undoubtedly, new friends will be made, and the sharing of stories of true inspiration from guests will have everyone leaving with a smile.

Designed to promote awareness of the challenges faced by many who have difficulty with eating as a result of their treatment, the event may feature items such as delicious crepes, soups, pasta dishes and desserts among other delights. This year’s event hopes to welcome back many of the chefs and restaurants who participated in the past, as well as many new establishments. It is our hope at SPOHNC, that Taste Events will also broaden the audience and bring oral, head and neck cancer awareness to many.

If your chapter is planning a Taste Event, please let us know the date and location by contacting SPOHNC at info@spohnc.org or by calling 1-800-377-0928. We’d also love to see post-event photos and hear your stories of success for a feature story in a future newsletter, along with recipes in the newsletter to tempt guests for next year’s events!

To find out if your local chapter is hosting a Taste Event, contact your local chapter facilitator (see Chapter listings in newsletter). If you’d like to get your chapter involved in your own Taste Event, contact SPOHNC at 1-800-377-0928 or e-mail us at info@spohnc.org.

To Whom It May Concern:

My name is Stephen Weber. I am the Principal of Destrehan High School located in South Louisiana.

At Destrehan High School, seniors are expected to complete and pass a Senior Project as a requirement for graduation. Special needs students are exempt from this requirement. However, Lee Oliver, an expert at the game of “Connect Four” had been insisting that we host a school wide “Connect Four” Competition at our school. Consequently, I suggested to Lee that this “Connect Four” Tournament be his Senior Project.

I explained to him that he couldn’t keep the money raised from this tournament, and Lee suggested that we give it to the Cancer ‘people’ who took care of my wife.

I gave Lee some information about your organization, SPOHNC, and Lee agreed to send any funds he raised to SPOHNC in honor of my wife, Becky, who is a survivor of tongue cancer.

Together, Lee and I planned the first “Lee Oliver Connect Four Challenge” tournament. Students competed at both of our lunch periods (nearly 60 students signed up) and the winners of both lunch periods competed against each other to determine the champion. Lee happily collected the money and then he sent a check to SPOHNC.

We’ll miss Lee Oliver when he graduates this spring. He’s a hard worker and an asset to Destrehan High School. I am very proud of Lee. Both Lee & I are pictured here at one of our football games.

God Bless you and your organization.

Sincerely,

Stephen Weber
ARIZONA-CHANDLER
Cancer Center at Chandler Reg. Med. Ctr.
1st. Wednesday, 5:30 – 7:30 PM
Monica Krise, MSW  480-728-3613
monica.krise@chw.edu
Dick Snider (ret.) 480-895-6019
rsnider326@aol.com

ARIZONA-PH OENIX
Banner Desert Medical Center
3rd. Wednesday, 4:30 – 6:30PM
Keri Winchester, MS, CCC-SLP  480-512-3627
Keri.Winchester@bannerhealth.com
Dick Snider (ret.) 480-895-6019
rsnider326@aol.com
Bette Denlinger, RN 602-439-1192
beneden@cox.net

ARIZONA-PHOENIX
Comprehensive Cancer Ctr.
St. Joseph’s Hospital and Medical Ctr.
1st., Tuesday, 5:30-7:30 PM Suite 650
Mary Schneider, Director  602-406-3882
mary.schneider@chw.edu
Joanne Currey, LCSW  860-778-5832
joanne.currey@centura.org

CALIFORNIA-LOS ANGELES-UCLA
UCLA Med. Pla., Rad/Onc
1st. Monday: 6:30-8:00 PM
Catherine DeStefano, RNC,OCN 860-892-2777
catherine.mcCarthy@lhmosp.org

CALIFORNIA-LOS ANGELES-UCLA
UM/Sylvester at Deerfield Beach, Ste.100
3rd. Tuesday: 1:30 PM-3:00 PM
Karen Moss, MS, CCC-SLP 352-342-1822
kmoss@nchmd.org

CALIFORNIA-LOS ANGELES-UCLA
Washington Hospital Center
2nd. Tuesday, 2:00-3:00 PM
Cynthia Clark, RD 202-877-3498
Cynthia.d.clark@medstar.net
Christopher Bianca, LCSW
christopher.a.bianca@medstar.net

CALIFORNIA-LOS ANGELES-UCLA
The Evelyn Trammell Voice & Swallowing Center
4th Tuesday, 4:00-5:00 PM
Laura Moon Cox, MSW  561-955-5897
lmoon@breh.com

CALIFORNIA-LOS ANGELES-UCLA
Englewood Medical Community Hospital
3rd. Thursday, 10:30 AM-12:00 noon
Joseph Bauer  941-474-0099

http://www.spohnc.org
E-mail-- info@spohnc.org
CHAPTERS OF SPOHNC

NEW YORK-ROCHESTER
Strong Memorial Hospital
1st. Thursday: 4:30-6:00 PM
Sandra E. Sabatka, LMSW  585-276-4529
Sandra_Sabatka@URMC.Rochester.edu

NEW YORK-STONY BROOK
Ambulatory Care Pavilion
1st. Wednesday: 7:30-9:00 PM
Dennis Staropoli 631-682-7103
den.star@hotmail.com

NEW YORK-SYOSSET
NSLIY-Syosset Hospital
2nd. Thursday: 7:30-9:30 PM
Christine Lanteri 631-757-7905
clanteri@optonline.net
Mary Ann Caputo 516-759-5333
mary.ann.caputo@spohnc.org

NEW YORK-WESTCHESTER
White Plains Hospital Cancer Center
2nd. Thursday: 7:00 PM
Mark Tenzer 914-328-2072
tenzer1@optonline.net

NORTH CAROLINA-ASHVILLE
Call for additional information
Kathleen Godwin 828-692-6174
kgodwin@morrisbb.net

NORTH CAROLINA-CHAPEL HILL/DURHAM
Comucopia House
3rd. Wednesday: 6:00 PM
Dave Gould 919-493-8168
dave.gould@da.org

NORTH CAROLINA-CHARLOTTE
Blumenthal Cancer Center
3rd. & 4th Thursday: 1:30-3:00 PM
Meg Turner 704-355-7283
meg.turner@carolinashealthcare.org

NORTH CAROLINA-CHARLOTTE
St. Rita's Regional Cancer Ctr.
1st. Tuesday: 6:30 PM
Dan Stack 972-373-9599
danrstack@aol.com

OREGON-MEDFORD
Providence Medical Center
2nd. Friday: 12:00-1:30 PM
Richard Boucher 650-269-8323
richard.boucher@hp.com

OREGON-THE WILLAMETTE VALLEY
Samaritan Reg CA Cntr Library
2nd. Wednesday: 5:00-6:30 pm
Lisa Nielsens 541-757-9882
HNCSurvivor@comcast.net

PENNSYLVANIA-HARRISBURG
Health South Lab 3rd. Tues.: 6:30 PM
Joseph F. Brelsford 717-774-8370
jfbrelsford1@mcm.com

PENNSYLVANIA-MONROEVILLE
Inter Community Cancer Center
Last Friday of month: 3:00 - 4:00 PM
Beth Madrishin 412-856-7740
bmadrishin@wpahs.org

PENNSYLVANIA-PHILADELPHIA
Penn Med Perelman Ctr Advanced Med
1 W. Pavilion Pt % Fam Conf Rm
1st. Wednesday: 9:30-11:00 AM
Micki Naimoli 856-722-5574
Tracy Lautenbach 215-662-6193
lautenbach@uphs.upenn.edu
Mia Benson Smith, 215-662-4641
mia.bensonsmith@uphs.upenn.edu

PENNSYLVANIA-YORK
Apple Hill Medical Center
2nd. Monday: 4:00-5:00 PM
Dianne S. Hollinger, MA, CCA-SLP
717-851-2601
Dhollinger@wellspan.org
Diane McElwain, RN, OCN, M.Ed
717-841-7100
dmcelwain@wellspan.org

VIRGINIA-CHARLOTTESVILLE
Regional Medical Center at Plano
1st. Tuesday: 6:30-8:00 PM
Polly Candela, RN, MS
214-820-2608
Polly.Candela@baylorhealth.edu
Emily J. Gentry, RN
214-820-2608

VIRGINIA-FAIRFAX
Inova Fairfax Hospital Radiation/Oncology
2nd. Wednesday: 5:30-7:00 PM
Corinne Cook, LCSW
703-776-2813
Corinne.cook@inova.com

VIRGINIA-FAIRFAX
Sentara Norfolk General Hospital
3rd. Thursday: 7:00 PM
Cynthia Gilliam 757-652-6653
beachdolphin@aol.com

WASHINGTON-SEATTLE
Evergreen Hospital Medical Center
Rad/Onc Ctr % Fam Conf Rm
1st. Tuesday: 6:00-8:00 PM
Kile Jackson 425-788-6562
kile.jackson@hotmail.com

WASHINGTON-SEATTLE
Swedish Med Ctr. 1 E. Conf Rm
3rd. Thursday: 6:00-7:30 PM
Susan (Sam) Vetto, BSN, RN, BC
206-341-1720
susavanette@vmmc.org
Joanne Fenn, MS, CCA-SLP
206-215-1770
joanne.fenn@swedish.org

WISCONSIN-MADISON
Univ. of Wisconsin Hospital
ENT Clinic Rm. G3/206
1st. Wednesday: 11:30-1:00 PM
Rachael Kammer, MS, CCC, SLP
608-263-4896
WISCONSIN-MILWAUKEE
Medical College of Wisconsin
Conference Rm. J, Rm. 1010
2nd. Wednesday: 4:30-5:30 PM
Tammy Wigginton, MS, CCA-SLP
414-805-5662
twiggint@mcw.edu

P.O. Box 53 Locust Valley, NY 11560-0053  1-800-377-0928

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