Support Goes a Long Way
Karrie Zampini Robinson, LCSW

While there has been considerable progress in cancer treatment and research over the past decade, living with head and neck cancer and its aftermath requires patience, grit, courage, stamina, hope and support.

Participation in a patient support group is just one of the tools to help you feel less isolated and may improve your capacity to cope with the challenges and uncertainties of a cancer illness.

Today, cancer survivors may find support groups based in hospitals, medical centers, and community organizations and online. Some of these groups are professionally led usually by social workers, nurses, psychologists or psychiatrists. Others are facilitated by survivor “experts” with a veterans help the rookies approach. In both realms the focus is to assist patients with the medical, emotional, and psychosocial aspects of living with the complexities of head and neck cancers. Connecting with “expert patient volunteers” or well-trained professionals can help you gather information and resources and strategize solutions to cope with obstacles you face every day.

Recent research from the University of California/San Francisco indicated that patients “who regularly participated in a multidisciplinary support group over a one year period did better in coping with swallowing and eating, communication and emotional well-being.” Results of this and other studies underscore the suggestion that including support groups as part of regular rehabilitation and therapy can be beneficial to your adjustment during and after treatment.

Living with diagnosis, treatment and rehabilitation of head and neck cancers can be a daunting challenge. “You are not alone” and “we have walked in your shoes” are group themes that can assist in your ability to navigate this illness. Through group participation you may be the recipient of resourceful, realistic and optimistic assistance, which may be important ingredients in your recovery and adjustment. This input can help you get a handle on your fears and uncertainties, help regain your sense of self worth and self-esteem and, ultimately find balance to move forward with your life with caution and confidence.

Editors Note: Karrie Zampini Robinson, LCSW is the Director of Clinical Programs and Senior Oncology Social Worker at Fighting Chance, a free Cancer Counseling Center, located on the East End of Long Island, New York. Karrie joined Fighting Chance in early 2005 after 16 years of counseling cancer patients as an oncology social worker and Director of the Post-Treatment Resource Program at Memorial Sloan-Kettering Cancer Center in New York City. Karrie is also a highly respected member of SPOHNC’s Medical Advisory Board.

SPOHNC - Dallas, Texas - How We Began
Dan Stack, Chapter Facilitator

The SPOHNC Dallas Chapter Support group is one of the oldest groups. The only way to begin a discussion about our group is to provide a brief history leading up to the first meeting in October 2001.

My very first SPOHNC meeting was in Atlanta, Georgia, in October of 1998. This was the second SPOHNC support group in the country and was a turning point in my recovery. After being told that I would be “back to normal” in four to six weeks after treatment, I was almost two months out from my last treatment and was still taking pain medication to eat solid foods (well, sort of solid…). I instantly realized that these 6 fellow survivors who were looking at me during the meeting knew more about the recovery process than anyone I had spoken to up until that point. They got it, they knew, and I very quickly became very close to my new SPOHNC “family” and looked forward to every monthly meeting.

Unfortunately, in the Spring of 2000, due to a job transfer, I needed to move to Dallas, Texas and I had to say good-bye to my Atlanta SPOHNC family. I loved Dallas but there was no SPOHNC Chapter here, so when I was laid off for 14 months later during the telecom downturn, I found myself with extra time. I was seeing Dr. Robert Sinard, a fine ENT Otolaryngologist, for my follow-ups. Dr. Sinard still maintains contact with us today even though he has been at the Vanderbilt-Ingram Cancer Center in Nashville, Tennessee for the past several years. I asked Dr. Sinard his thoughts about a Head & Neck support group. He was quite interested and introduced me to one of his senior nurses, Hope Andresen, who

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thought a group was desperately needed but just didn’t have the time to organize and facilitate one.

Within a couple of weeks, she arranged a meeting room for us at the Baylor facility in Irving-Coppell, where we still meet today. All I needed now was to get the word out - the process had begun.

I worked with Survivor and SPOHNC Founder, Nancy Leupold, who searched the SPOHNC database for anyone who had contacted them from the zip codes in and around the Dallas, Fort Worth area. I drafted a letter, on SPOHNC letterhead, explaining the formation of the new chapter. The letter was sent to anyone who had requested information from our area. I also made inquiries at Baylor University Hospital in Dallas and was put in touch with the Chaplain’s office (they assist all support groups). They already had several requests for a Head & Neck centric group but never had anyone available to facilitate one. They also introduced me to Dr. John O’Brien at Baylor, who helped me navigate the Baylor system and continues to support us today. I spoke with Baylor Irving Cancer Center Director, Dr. Greg Hecht (who now has his own oncology practice and still supports our group), to let him know about the formation of the new SPOHNC Chapter. At each meeting, I left a copy of the letter I had written, talking about the formation of the chapter, along with some SPOHNC brochures.

We started with 6 survivors and a couple of caregivers attending the first meeting in October, and even though some have moved from the area, we still have four that either attend regularly or stay in touch and visit when they are in town. During the first several meetings, we had the Baylor Chaplains and several other local Oncology Professionals visit our meetings to make sure we were providing a benefit to the patients that they had referred. Referrals from the Oncology community are our lifeblood and will keep a group interacting with new survivors, who are crucial to the longevity of a group. We quickly grew to a group of 15 to 20 regular attendees and the second Chapter started not long after that at the main Baylor University Hospital, where Jack Mitchell co-chaired that group along with the Chaplain’s group there. Today, we have four active groups in the Dallas Forth Worth area. That was the beginning.

What made the group so successful and how is it still going strong after almost 12 years? For many reasons, really, but it boils down to the basics - Passion, Commitment, Leadership, Focused Vision, Engaged Team Members and Communication. It sounds like the core attributes of a successful company, doesn’t it? Well, it is very similar, sort of.

Passion

When new survivors visit their first SPOHNC meeting, it is a “life changer.” No matter where in the “battle” cycle they are - pre or post-treatment - it doesn’t matter. The fact that you finally connect with others who have “Walked In Your Shoes” and who are able to help you cope with quality-of-life issues, or just confirm that at some point during the long recovery, you will settle into your “New Normal” is the focus. Some visitors are very appreciative of the support and information they receive and use it to move on with their lives, and others become passionate about helping other survivors and become regular attendees, to be there to help other first time visitors.

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Commitment

Commitment and passion kind of go hand-in-hand initially, but commitment typically provides the endurance factor that helps us overcome obstacles that get in the way of our day-to-day obligations. Commitment comes into play when we have only 3 or 4 people attend a meeting (and that has happened more than once during our 12 years), when that voice in your head asks “are we still being effective and adding value to new head and neck patients?” Commitment is trying to attend every meeting, even though each of us has life constantly pulling us in different directions that demand our time.

Leadership

I facilitated meetings in my corporate life so I had already developed the basics, although SPOHNC Corporate sends out a Facilitators manual for new chapter leaders that is very helpful for those that haven’t had previous experience. Our meetings run fairly smoothly in the sense that sometimes we have discussions that bounce back and forth between members, but everyone has the opportunity to contribute to the discussions or ask for feedback on an issue before we end each meeting. Sometimes we have specific topics for discussion, whether we have guest medical professionals visit us, or focus on nutrition, discuss products that help with our quality of life issues, or whether we have a “Tribute to our Caregivers” meeting, which is one of my favorites.

Focused Vision

We keep it simple. The focus of every meeting is to promote awareness of head and neck cancer and provide support to anyone attending, who has gone through treatments or is a caregiver in need of support trying to assist a loved one dealing with the disease. We are there to answer questions and provide information and support to those that are in the “fog” of their cancer battle, and to help each other. After 12 years, I still come away from most meetings learning something new.

Engaged Team Members

This is truly the most important cornerstone of having a successful group. No single individual can provide the kind of feedback necessary to help new visitors who attend a meeting because we all respond differently to treatments, had slightly varied diagnoses and we all had some variations to our treatment plans. The true benefit comes from being able to provide feedback from different perspectives on similar challenges. For example, those who are treated with radiation today will typically experience recovery sooner and settle into their “new normal” much quicker than those of us that had radiation 15 years ago, due to the technological advancements in radiation therapy. We all have a lot going on in our lives, but without a doubt, members that are committed to attending as many meetings as their busy lives will allow are what makes a group thrive, because you never know when someone new will walk through the door. If you don’t have the human capital there to provide support, you may miss an opportunity to help those in need, very much like each one of us were helped when we attended our first meeting.

Communication

This is probably as important as having engaged members in a sense that people that come to us for help need that help more than just once a month. Since the beginning, we have had an email distribution list that is an optional service provided to our members and visitors, whether they choose to have their email address displayed in the “Send To” header or “Blind Copied” so their address is not displayed. There are times when a member has a question or needs help, but can’t wait until the next meeting. This cornerstone allows contact and feedback from our community of members in real time. We have some medical professionals, both physicians and nurses who have stayed on our distribution list, and they frequently provide helpful responses to our topics from a professional perspective. We also have email members outside the Texas area who don’t have a chapter nearby to attend, so this has helped them over the years to cope with certain issues.

One additional item to consider when starting a chapter is when you will meet. We may be one of the few groups that meet on a Saturday. We decided that Saturday mornings from 10:00 until noon might help those folks that were still working a full week. This left the rest of the weekend for family. The other three groups in the Dallas Forth Worth area all have different meeting times so it works for those with changing schedules. Jack Mitchell, who has retired since co-chairing the Baylor-Dallas group, now coordinates information among all groups.

I asked a couple of our members what our group means to them and here are their responses -

“Feel our group is a wonderful resource of information as we talk about and compare our treatment experiences and personal survival issues. Cancer changes everything. Our group gives encouragement and guidance, which in turn, gives hope to all in their cancer journey…” ~ Carol Humphries

“I attend regularly because it helps me understand the meaning of the term “new normal” and to be able to help others gain that same perspective is very rewarding… We always find a reason to laugh…” 

~ Bob Broesamle

Our Dallas Group has been successful because its attendees are committed to helping others who are in the same place mentally that they were when they first visited a SPOHNC meeting and now attend meetings on a consistent basis.

* * * * *

SPOHNC - Palm Coast, Florida

With You All the Way

Amy and Lewis Beilman, Facilitators

If you’re reading this in a copy of the SPOHNC newsletter, I don’t have to go into great detail about how throat cancer changes your life and puts into motion a new set of rules. When my husband Lewis was diagnosed with throat cancer in June 2011 the diagnosis of cancer came as a complete surprise. Lewis had a history of oral issues, visiting ENT doctors over several years, which included biopsies. They were always “auto immune” disorders. This

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time, when his throat bothered him again, there were fires in the area where we live in Florida. We chalked his issues up to the smoke in the area.

When the problem persisted, he said he thought he needed to see another ENT doctor. I thought, here we go again. I asked him to go to our regular general practitioner. When our Doctor looked in Lewis’ throat, his first comment was “That’s the worst case of tonsillitis in an adult that I have ever seen”. He then paused, thought about it, and said, “let’s do a CAT scan”. The next day the call came - the doctor wanted us to come in to the office to discuss the test results. When you’re called in to “discuss” the results, that’s not good. And so, that’s how the journey started. A tumor on each tonsil and suspicious lymph nodes.

In a heartbeat, our lives changed. We got treatment at the Mayo Clinic. Surgery was considered at first, but due to the large size of the main tumor and the difficulty to remove it, it was decided to do only chemo and radiation. Thinking back, several things stand out to us now. We were told that they were going to “go for the cure.” At that time we did not know the importance of that statement. Some cancers are not self-contained and are more susceptible to spreading. Some cancers are not “curable”. Their goal was to completely eradicate the cancer with the result being a “cancer free” life for Lewis and Me. We were one of the lucky patients, although at the time, that’s not how we felt.

The second surprise was that in Lewis’ case, even though the surgery could not be performed, the statistics showed that the outcome with no surgery and only chemo and radiation was the same. This was also great news because if the surgery were performed, it would have to be drastic and could cause permanent disfigurement.

My transition from an active retiree to “Nurse Ratchet” happened quickly. I had no time to prepare or study for this role, and this metamorphosis was not an easy one. I literally had flunked candy stripers as a Brownie 60 years ago. Luckily, a good friend did some internet research for oral cancer support organizations, and thankfully, she suggested contacting SPOHNC. I did, and was immediately impressed. SPOHNC’s National Survivor Volunteer Network of others who had already been on the journey, was a huge help for both of us as we began the journey. There were no local chapters of SPOHNC within 100 miles of us at that time so we utilized the match program. When I reached out to survivors across the U.S., I found there were people all over who had similar experiences and were willing to share information. Those conversations with others helped us deal with all the unknowns... like dry mouth, feeding tube questions, sores in the mouth, not being able to lay flat without gagging, the mucous, and on and on. I was so grateful for the help. There was also a facilitator in California - Valerie - who was so helpful and answered all my questions that were never ending. I told Lewis that if we came out of this cancer free, we were going to give back by starting a local chapter of SPOHNC right here in Palm Coast. He said, “If and when I get back to normal (the new normal), I’m with you all the way.”

One year later, in June of 2012, Lewis was on his way to getting back to “normal”. It was a tough year. Lewis had been through quarterly check ups after radiation and chemo, and all showed that he was cancer free. Even though a number of after effects still persisted, we held our first SPOHNC Chapter Support group meeting, in the Clubhouse of the gated community where we live. SPOHNC headquarters in Long Island, NY had been giving us counsel about how to set it up and what to expect etc. We received SPOHNC materials and guidelines which helped us tremendously along the way.

Lewis and I had been to one general cancer support group prior to this and it was everything we didn’t want ours to be. In that meeting for 45 minutes a distraught woman sobbed about having had cancer 10 years ago and was still terrified that it was coming back. After sitting through that experience we decided our support group was NOT going to be a pity party. We weren’t sure what it would evolve into, but for sure, we knew we wanted it to be a place where it was safe, a place to share information, a place to support one another and a place that gives hope to others.

I had a background in facilitating groups, so I wasn’t nervous about that part. What we were both nervous about was if anyone would show up. Well, as they say, “if you build it, they will come.” Lewis made certain we got mention in our local papers. He contacted radio stations and local internet based news services. We put flyers for our support group in the hospitals, doctors offices, dentist offices and on local bulletin boards. We started with six participants just over one year ago. The word got out, and now we have an attendance list of 35 people. Not all are able to attend on a monthly basis. We average around 20+ at each meeting. Unfortunately, each meeting has been bringing in new people just starting the oral cancer journey.

At every meeting, we ask participants to share where they are on their own journey. They are encouraged to ask questions, and offer their advice to others who have similar issues. Every new participant is called on to share their own story if they are comfortable doing so. What’s special about this group is their overwhelming desire to give back to others. They all look forward to our monthly meetings. Our group also welcomes spouses, family members and caregivers in addition to the cancer patient. Occasionally we have a guest speaker for 15 minutes.

Several months ago, a new local ENT Doctor at our hospital heard about our group, and reached out to “partner” and support us. He offered the hospital as a meeting location, instead of the private location where our meetings had been held. We discussed it as a group and unanimously agreed that it would be great as long as we could keep our SPOHNC affiliation and our autonomy. It’s been a great relationship and is more convenient for everyone.

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This past April, we did our first fundraiser and raised over $2,000 for SPOHNC. We were also featured in our community’s newsletter and our local newspaper with stories about our support group and its success. Everyone is so supportive of this cause. It sometimes is overwhelming.

We are grateful to SPOHNC for their support and for their dedication to get as much information as possible to anyone who needs information about oral, head and neck cancer. Each and every time a new person contacts us and joins the club that no one really wants to join, we all try to make sure that a new member walks away feeling better. Lewis and I feel so proud to have made a difference in the community and to have the support of SPOHNC who is there for all of us.

Congratulations and very best wishes to Nelson and Bette Denlinger, of Mesa, Arizona. Bette is a National Survivor Volunteer Network volunteer, a past Facilitator of her local SPOHNC Chapter Support group and a long time friend of SPOHNC.

Nelson and Bette recently celebrated 50 years of wedded bliss, at a special drop-in reception held at the home of their daughter and son-in-law, Deb and Jesse Spurgin, in Chandler, Arizona. SPOHNC received a beautiful gold invitation by mail, along with the photo seen here. Sorry we couldn’t attend, but we were with you in spirit as you enjoyed a fabulous evening filled with fond memories, fine food, family and friends. What a beautiful couple on their wedding day! Congratulations and best wishes for many more!

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HEAD AND NECK CANCER NEWS

ECC: Hyperfractionated Radiotherapy Improved Survival for Head and Neck Cancers

October 2, 2013 - The use of altered fractionation radiotherapy increased overall survival in patients with locally advanced head and neck cancers when compared with standard radiation, according to the results of a meta-analysis presented at the 2013 European Cancer Congress in Amsterdam.

“The improvement in survival is marked for patients in the hyperfractionated regimen, with an absolute benefit of 8.1% at 5 years,” said Pierre Blanchard, MD, a radiation oncologist from the Institut Gustave Roussy, Villejuif, France, who presented the results.

Blanchard and colleagues undertook a meta-analysis that examined randomized trials comparing standard radiation therapy with altered fractionation radiation therapy with or without concomitant chemotherapy in patients with local head and neck squamous cell carcinomas.

Fractionation was defined as either standard, 5 fractions per week for 7 weeks, or accelerated. Altered therapy could have been either hyperfractionated; (10 fractions per week for 7 weeks resulting in a higher dose); accelerated, which is the same dose given over 6 weeks; or very accelerated, which is a low dose given in about 3 weeks.

The researchers collected data from 31 trials representing more than 11,500 patients. After 7 years of follow-up, the data show that the higher dose intensity of altered fractionation radiotherapy improved outcomes in these patients.

Altered fractionation radiotherapy improved overall survival (3.1% gained at 5 years, corresponding to a reduction of the risk of death of 6%) and progression-free survival (reduction of the risk of progression or death of 10% at 5 years), Blanchard told Cancer Network. “While the acute side-effects of altered fractionation radiotherapy are increased compared to those experienced by patients on standard fractionation radiotherapy, the late side-effects are comparable and, overall, side effects are more than compensated for by the significant increase in survival in the altered fractionation radiotherapy group,” Blanchard said.

Finally, a secondary analysis has shown that altered fractionation radiotherapy was inferior for overall survival to standard fractionation radiotherapy when the latter is associated with concomitant chemotherapy.

Therefore, Blanchard said that in order to use altered fractionation radiotherapy in advanced cases of stage III or IV cancer, those patients cannot be candidates for concomitant chemotherapy.

The meta-analysis was carried out by an international collaboration known as MARCH, including many countries in Europe, the USA, Canada, and Brazil, Egypt and developing countries through the International Atomic Energy Authority. The researchers said that the survival benefits are mostly related to improvements in locoregional control, the area located close to the primary tumor being by far the most common first site of relapse in this disease.

“These data are a major advance for understanding the role of AFRT in head and neck squamous cell carcinoma,” Blanchard said in a press release. “By carrying out a large-scale analysis such as this one, we believe that we have provided enough evidence to indicate that doctors should recommend AFRT as a validated treatment option for head and neck cancer patients.”

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From the Executive Director…A Salute to SPOHNC’s Volunteers!

Support as we know it comes in many different shapes and forms. It can reflect bravery, advocacy, assistance, help, to act with, to keep from losing courage, to comfort and one very important definition is to keep going.

Many of the words above describe the ways that our volunteers support survivors who have gone through a journey unlike any other - each one knowing how devastating this disease can be and understanding that lending their guidance can be of the utmost help going forward. It is a known fact that support groups have been shown to be of great benefit to individuals with cancer. This issue of “News From SPOHNC” is dedicated to all of our volunteers who have supported, encouraged, and comforted a patient going through their journey with oral, head and neck cancer. Many others made sure their community members - especially healthcare professionals - are aware that a SPOHNC chapter exists in their town, and others made it their mission to grow our organization and support others by developing a SPOHNC chapter in their own community.

When I began on my own path with SPOHNC, 36 chapters existed. This year alone, thirteen new chapters were created, bringing the total number of SPOHNC chapters to 125, throughout 39 states. This is a fine testament to all that our volunteers can accomplish, as well as to how much they are valued in this organization. With their ongoing efforts, we can continue to grow and reach out to those cities and states where many patients need our support.

SPOHNC knows how devastating this disease can be–especially for those who are going through the journey alone. With the continued help, motivation, dedication and selflessness of our volunteers, SPOHNC has the ability to continue Nancy’s vision of supporting survivors through our Outreach Programs and the many other resources that we offer.

SPOHNC values each of our volunteers, and we are inspired by the incredible amount of care and kindness that you show to others. We take pride in your work and we are incredibly thankful for each of you who sacrifice one of your most precious resources - your time - to ensure that we are able to touch the lives of those who need SPOHNC the most. You all bring so much to SPOHNC: your experiences, skills, advice, inspiration and friendship. Your strong advocacy helps us all to continue our fight to protect and support each patient.

This holiday season we embrace all of the effort you have put into making a difference in the life of a patient and their family. Our hearts are filled with deep gratitude.

May the peaceful beauty of this holiday season bring you many blessings of joy, health, hope and laughter. Thank you all for all you do, and for your support!

SPOHNC salutes your bravery, strength and commitment. You are all truly magnificent.

Fondly,

Mary Ann Caputo
Executive Director

Visit the SPOHNC website at www.spohnc.org
A TIME FOR SHARING...Valerie’s Story

I must confess I promised SPOHNC I would write my ten-year survivor story. Only now it’s fourteen years. Can you say procrastination? How time flies, when you’re having fun recovering from cancer. I’d better finish this before it becomes my fifteen-year survivor story.

To recap my story (published in the SPOHNC newsletter, Summer 2005) during the Christmas season of 1998, whilst decked the halls, and hanging the balls, I felt an olive-sized lump in my neck. For the next three months, as I came down with various infections, four different ENT doctors misdiagnosed me. But the ever-present lump made me nervous, and I finally saw an ENT surgeon, specializing in Head & Neck diseases. After a biopsy he told me, what I never expected to hear “I’m sorry, but you have stage III, squamous cell carcinoma of the right tonsil”--Whaaaat! How could that be? I didn’t smoke, or drink.

The novel writers cliché about going numb, actually exists. After the word cancer, I did not hear another word my surgeon said. He prescribed two surgeries, then radiation. Within a week I was admitted for my first surgery, which was a radical tonsillectomy, including half of my palette. Painful as it was, he wasn’t finished with me. Ten days later, I was readmitted for a neck dissection. The admitting lady said, “Haven’t I seen you before?” I said, “Yes, I was here for surgery ten days ago, and I liked it so much I came back for more!” Next, I had my radiation-field teeth extracted. After six weeks of recuperation, and feeling better, I started radiation. Fourteen years ago, the more sophisticated technology of today did not exist. They strapped me on a table, tattooed me, and radiated everything within a hundred miles around my head.

Head & neck cancer radiation is daunting, to say the least. Unlike other parts of your body, it severely affects your essential daily luxuries, like eating, breathing, sleeping, etc. There’s supposed to be about a two-week grace period before you feel the side effects from radiation. However, I’m such a petite, dainty flower that after the first few days, I started to feel some mild symptoms. And, it was downhill from there. My radiation schedule was interrupted twice. I became dehydrated because I couldn’t even swallow water, and needed re-hydrating like a dried mushroom. Later, I developed a blood clot in my leg, probably associated with inactivity and the steroids prescribed to address the inflammation. The cessation of treatment made me nervous, but my doctor assured me that it would not affect eradication of the tumor. I point these things out not to scare you, because everyone tolerates radiation differently, but to illustrate the need to be aware of what your body is telling you, and to be sure to inform your doctors of any problems.

Guided imagery helped me with relaxation, and every day, when the radiation beams were shooting into me, I imagined a Star Trek machine zapping the cancer cells until they exploded. I know that attitude, and humor is so important in life and recovery. Going through treatment, I watched all the funny old sitcoms, and movies I could find. I was too fatigued to laugh out loud, but I knew that laughing in my mind was just as therapeutic.

The popular phrase “Radiation is the gift that keeps on giving” is so true. As soon as they finish treatment, patients expect that they will bounce back to normal. Unfortunately, it’s a slow recovery. For about three months after finishing treatment, I was down for the count with fatigue, burning tissues, and eating problems. With a weight loss of 23 pounds, I was indeed a shadow of my former self. At that time, feeding tubes were not standard, and my doctor did not like the possible infections associated with them. He also knew that I was well-informed about the importance of healthy nutrition.

It seemed as though all of a sudden, from one week to the next, the fatigue lifted, and I gained back most of my old energy. I started exercising again, and although I grew stronger, that’s when I lost the last six pounds, because my throat still hurt, and I wasn’t eating enough calories to gain. I lived on my neighbor’s lovely organic eggs, any moist, pureed food I could get down, and my own recipe for nutrition-dense milkshakes. (Page 11 in the SPOHNC cookbook).

I think I continued to heal slowly for about four years. I still do not have the normal saliva I had before radiation, however there are prescriptions, and over the counter products that do help with that. Acupuncture for dry mouth helped me tremendously. Dental issues were not a problem until recently, when my teeth started to chip and break. Occasional neck stiffness bugs me, and I sometimes have trouble swallowing, but overall the “new normal” makes for a happy life. I have become “The Buffet Queen.” I eat anything that’s not nailed down, with the exception of dry foods. I gained back ten pounds, and have the girlish figure I had in my twenties (except for gravity, but that’s another sad story).

Going through treatment I vowed that if I lived through it, I would help those having to endure the same journey, so, in 2000, I started the San Diego Chapter of SPOHNC. My group started small, and sputtered along until my efforts at spreading the word started getting results. I ran ads in everything, exhibited at every cancer-related event I could get to, designed and made SPOHNC brochures for the local chapter, and ran around San Diego distributing to anyone who would listen. We now meet every first Saturday at noon. The only oral, head and neck cancer support group in San Diego is now thriving.

I run an upbeat support group. I start every meeting with a clean joke. One time I forgot to tell a joke, and someone said, “Hey, you can’t start yet. You haven’t told one of your terrible jokes.” Laughter may not be the best medicine, but it sure comes close. I tease new patients, “Geesh, you guys today have it easy. When I went through treatment, I had no mask, no feeding tube, no therapy, no support group.” My regulars chime in and say, “Yeah, yeah, we know, and you had to walk ten miles each way in the San Diego snow to get to treatment!” Even people, who are anxious, and in pain, laugh with us.

As well as educating patients, I book relevant speakers for the group. Most professionals I approach are generous in taking time from their busy schedules to continued on page 8

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come and talk to us. We have had nurses, ENT doctors, radiation/oncologists, cyber knife experts, social workers, patient advocates, therapists, psychologists, dieticians, nutritionists, life coaches, acupuncturists, etc. I recently sent a translated version of a SPOHNC newsletter to a prominent medical contact in Mexico.

I am a volunteer for SPOHNC’s National Survivor Volunteer Network, which matches survivors with anyone needing help or advice. It’s very rewarding to talk with someone who is nervous, anxious, or downright scared, and encourage them through the long, dark tunnel of treatment, and see them come out at the other end, hopefully smiling. I tell everyone the Big C stands not for cancer but for COURAGE.

Of course, there are dark moments, when sadly we lose someone. That’s very hard, and brings home the gift of being a survivor. Treatment modalities for oral, head and neck cancer have come a long way, and due to the rise in oral, head and neck cancer patients, more research is being done. The future holds the promise of hope, for oral, head and neck cancer patients.

I wish you all well.

Valerie D. Targia,
The “new normal” Coordinator/Facilitator,
San Diego Chapter, valtargia@yahoo.com

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**Butternut Squash Soup**

1 lb. butternut squash, peeled and cut into chunks (3 c. cubed)
4 c. reduced sodium chicken broth
1 c. low fat sour cream
1 Tbsp. butter
½ tsp. ground cayenne pepper
½ tsp. kosher salt
white pepper
1 Tbsp. sugar (optional)
chopped chives for garnish

Combine squash and broth in large saucepan. Bring to boil over high heat. Reduce to medium, cover and simmer until squash is tender (about 20 minutes). Uncover and cool. Puree squash in blender or food processor. Return puree to saucepan and place over medium/low heat. Stir in sour cream, butter and cayenne. Add salt and white pepper. If squash lacks sweetness, add sugar. Cook soup til thoroughly heated but not boiling. Ladle into bowls and garnish with chives. Serves 5.

~ Maria Folchetti, New York
(From SPOHNC’s Eat Well Stay Nourished A Recipe and Resource Guide for Coping With Eating Challenges - Volume 2)
# CHAPTERS OF SPOHNC

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

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