



**S•P•O•H•N•C**

A PROGRAM OF SUPPORT  
FOR  
PEOPLE WITH ORAL  
AND  
HEAD AND NECK CANCER

## TISSUE BANKING FOR HEAD AND NECK CANCER

ELIZABETH HAMMON, MD

When a patient undergoes a biopsy for initial diagnosis or surgical treatment for cancer, tissue samples are removed and sent to the institution's pathology department for routine testing and diagnosis. The tumor tissue is always used to define the diagnosis and stage of disease by the local pathologist. After this process is completed, the remaining tumor samples are stored in the institution's pathology department to be used for future diagnostic purposes or for research. Patients wishing for their tissue to be used for research, after the diagnosis process is complete, will sign a consent form for their tissue samples to be sent to a tissue bank.

A tissue bank is a repository that is established, usually by a non-profit organization, for the collection of donated tissue samples and cells from many sources. These donated tissue samples and cells may then be used in future research. The Radiation Therapy Oncology Group (RTOG), a multi-institutional cooperative cancer study organization funded by the National Cancer Institute with almost 30 years of experience in conducting clinical trials is an example of a tissue bank. This organization comprised of 250 major research institutions nationally and in Canada, currently has more than 40 active studies that involve radiation therapy either alone or in conjunction with surgery and/or chemotherapeutic drugs. In early 1997, the RTOG tissue bank was awarded funding from the National Cancer Institute (NCI). This tissue bank is a central fixed tumor tissue repository for the RTOG including tumor tissue from all sites under study by the group as phase III clinical trials. The tissue bank collects tissue samples from RTOG phase III trials for cancers of prostate, bladder, lung, head and neck, esophagus, and malignant glioma.

Clinical trials in head and neck cancer are important studies to help patients and physicians find the best treatments. Such studies compare one treatment with another in an attempt to identify which

ones will provide patients with greatest benefit. Since the treatments are expensive, time consuming and might lead to complications, physicians continue to search for ways to determine which patients are most likely to benefit. Patients on clinical trials are always asked to contribute remaining tumor tissue samples to tissue banks so that the samples can be used to predict which patients are most likely to benefit from each treatment. If patients agree to contribute tissue, tissue samples are obtained from pathology departments and sent with only coded information about the donor to the tissue bank, rather than patient names. Samples are stored securely and confidentially, so that no one can determine identity or other patient information. Since tissue that is used for this purpose is removed at the time of surgery or biopsy, the permission to use this tissue will not lead to any additional procedures or expense on the part of the patient.

Investigators may write a proposal to do research requiring the testing of tissue. Areas of studies may include how normal cells become cancer cells, how our bodies react to those cancer cells, how cancer cells spread in the body, and how cancer cells respond to treatment. Investigators with good ideas about how to select patients who are best suited for specific treatments will apply to use the tissue samples in research studies. Their proposals are carefully reviewed and approved if they are considered valuable. Researchers can then access the tissue bank samples from a specific trial to answer important questions such as which patients will have improved survival based on this treatment? Which patients might be harmed by this treatment? Once a study is approved to access donated tissue samples, samples are prepared and sent to investigators who perform the tests. These tests take weeks to months to perform. An example of a test which has been successfully done on head and neck cancer is the evaluation of Epidermal Growth Factor Receptor (EGFR). Tumors of head and neck can overexpress this cell surface protein.

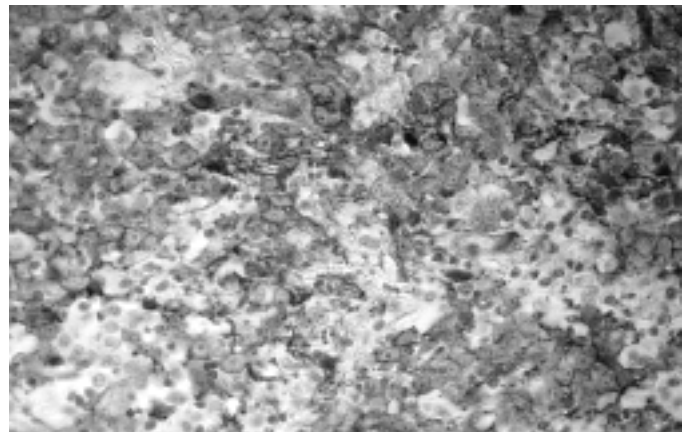


Fig 1. Head and neck cancer weakly expressing EGFR. The dark outline of each cell represents the location of the EGFR along the cell membrane. It is irregular and incompletely surrounding each cell.

TISSUE BANKS continued on next page



SUPPORT FOR PEOPLE WITH  
ORAL AND HEAD AND NECK CANCER

**S•P•O•H•N•C, INC.**

P. O. BOX 53  
LOCUST VALLEY, NY 11560-0053

**BOARD OF DIRECTORS**

**Nancy E. Leupold, MS, President**  
**James J. Sciubba, D.M.D., Ph.D., Vice President**  
**Jean O. Cashin, Secretary**  
**Walter E. Boehmler, Treasurer**  
**Maria DeMarco Begley, Esq.**  
**Louis Frillmann, LaD**  
**Karrie Zampini, LCSW**

**MEDICAL ADVISORY BOARD**

**David M. Brizel, M.D.**

Duke University Medical Center  
**Linda K. Clarke, MS, RN, CORLN**  
Greater Baltimore Medical Center

**David W. Eisele, M.D.**

University of California San Francisco

**Keith Heller, M.D., F.A.C.S.**

North Shore-LIJ Health System

**Alex Keller, M.D., F.A.C.S.**

North Shore-LIJ Health System

**Jesus E. Medina, MD**

University of Oklahoma Health Sciences

**Eugene N. Myers, M.D., F.A.C.S.**

University of Pittsburgh School of Medicine

**David Myssiorek, M.D.**

North Shore-LIJ Health System

**Herman Oliver, M.D., F.A.P.A.**

North Shore-LIJ Health System

**David G. Pfister, M.D.**

Memorial Sloan-Kettering Cancer Center

**Jed Pollack, M.D.**

North Shore-LIJ Health System

**James J. Sciubba, D.M.D., Ph.D.**

Johns Hopkins Medicine

**Elliot W. Strong, M.D., F.A.C.S., Emeritus**

Memorial Sloan-Kettering Cancer Center

**Denise M. Vey Voda, M.A., D.D.S**

North Shore-LIJ Health System

**Everett E. Vokes, M.D.**

University of Chicago Medical Center

**David P. Wolk, M.D., F.A.C.S.**

North Shore-LIJ Health System

**Karrie Zampini, LCSW**

**NEWSLETTER EDITOR**

**Nancy E. Leupold, MS**

**WEBMASTER**

**Barry Sebastian**

*News From SPOHNC* is a publication of  
Support for People with Oral and Head and Neck Cancer, Inc.  
Copyright ©2004–2005

DISCLAIMER: Support for People with Oral and Head and Neck Cancer, Inc. does not endorse any treatments or products mentioned in this newsletter. Please consult your physician before using any treatments or products.

**IN THIS ISSUE**

SPOHNC's 15th Anniversary.....	4
A Time for Sharing.....	6
“Tricks of the Trade” What Works for YOU.....	7

**COMING IN NOVEMBER 2006**

“Intraoperative Radiation Therapy for Head and Neck Cancer”  
Kenneth Hu, M.D. and Louis B. Harrison, M.D.

TISSUE BANK continued from page 1

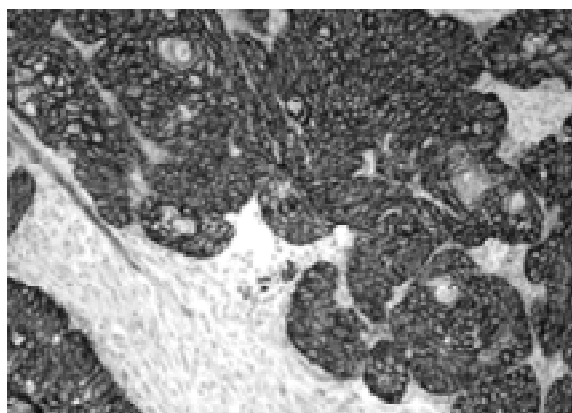


Fig. 2. Head and neck cancer strongly expressing EGFR. The dark outline of each cell represents the location of the EGFR along the cell membrane.

There are drugs that target this protein which are used to treat head and neck cancer including Iressa, Erbitux, and Tarceva. Studies that help us understand the way this protein affects head and neck cancer will help future research. and treatment outcomes.

When the next trial is designed for patients, physicians use the data from these studies to decide who should receive which treatment. For example, studies are trying to define which patients will benefit from treatment with Iressa. This drug's benefit was predicted because it was found through tissue bank studies that many patients had increased expression of EGFR on the surface of their cancer cells, which made it likely that they would respond to such drugs. Current studies are trying to refine those observations so that only those patients who will respond will receive treatment with such drugs.

Tissue banks make significant efforts to obtain samples on every patient on each clinical trial so that results from testing the tissue will provide the best opportunity for discovering important information concerning a patient's response to treatment. The results are compromised when all the samples are not obtained. Typically, the tissue bank only gets about 50% of the samples they request. This is very discouraging to everyone involved. If all the samples are not obtained, the statisticians have a harder time analyzing the data to find potential benefits. Drugs, like Iressa, which may be beneficial to patients may be erroneously judged to be of no benefit because of insufficient data to make valid conclusions.

Samples are not provided for various reasons. In some cases, all of the sample was used to determine the diagnosis on the patient so he or she could get treatment. Other times, the sample is so small that it cannot be easily used for some studies. Often, however, it is because the institution where the sample was examined refuses to release the sample to the investigators even though the patient has given permission for the sample to be released. They claim that they are protecting the patient's rights by keeping the samples safe or claiming that it is too much effort to find and send the samples, even though the institutions are always paid at least a nominal amount for such efforts. If a trial requires that samples be sent in order for the patient to be eligible, such actions can deny patients access to potentially valuable studies.

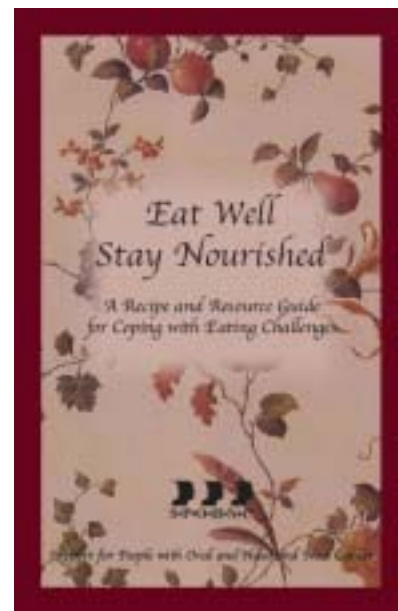
TISSUE BANK continued on page 3

This is a serious problem for tissue banks which patients can help to solve. Patients need to be very out-spoken in supporting the transfer of their tissue samples into tissue banks. They can notify institutions, write articles, and try to elicit public support for tissue banking in local communities. The National Cancer Institute is working hard to make it easier for tissue samples to be obtained for research and to be sure that patients understand the issues. The NCI currently supports several human tissue resources, including the Cooperative Human Tissue Network, Clinical Trials Cooperative Groups, Cancer Family Registries, and tissue banks located at individual Specialized Programs of Research Excellence (SPOREs). These resources provide thousands of valuable biospecimens annually to researchers for many types of scientific investigations. NCI has also sponsored teleconferences for advocates featuring the leader of this effort at NCI, Dr. Carolyn Compton. More information about the issues surrounding tissue banks can be obtained from the NCI website:

[www.ncilists.cancer.gov](http://www.ncilists.cancer.gov), and on the NCI directors update: [www.cancer.gov/directorscorner/directorsupdate-11-18-2003](http://www.cancer.gov/directorscorner/directorsupdate-11-18-2003). The RTOG web site also provides information on its tissue bank. It can be accessed at [www.rtog.org/tissuebank](http://www.rtog.org/tissuebank).

*Editor's Note: M. Elizabeth H. Hammond, MD is Professor of Pathology at the University of Utah School of Medicine and Associate Professor of Internal Medicine (Cardiology) at the University of Utah School of Medicine. She is an immunopathologist at LDS Hospital where she has supervised a predictive cancer factor and general immunohistochemistry reference and research laboratory for many years. She is the current director of the NCI funded tissue bank of RTOG and serves as vice chair of the Group Banking Committee of NCI as well as the chair of the access subcommittee for the Group Banking Committee. These committees manage the activities of all the cooperative cancer trial tissue banks in the USA. Dr. Hammond is also chair of the Education Committee for the College of American Pathologists and lectures and writes extensively on subjects related to her interests.*

## SECOND PRINTING



*“Eat Well – Stay Nourished:  
a Recipe and Resource Guide for Coping  
with Eating Challenges”*

[www.spoHNC.org](http://www.spoHNC.org) 1-800-377-0928

## SPOHNC CELEBRATES FIFTEEN YEARS

The weather was perfect! The Marriott LaGuardia Hotel was ready! Guest speakers were arriving! Exhibitors were preparing to set up. And survivors and their families and friends were making their way to SPOHNC's 15<sup>th</sup> Anniversary Conference and Celebration of Life. No one really knew what to expect, as this was the first conference and celebration of life that SPOHNC had organized. Even the SPOHNC team of Nancy Leupold, Janine Cortese and Mary Ann Caputo was not sure how the event would go. But they did know from speaking with survivors and chapter facilitators that when survivors and their loved ones come together, the environment is soon filled with camaraderie and warmth. A very special energy is generated.

This was true of our Conference and Celebration of Life, which began on Friday evening with an informal meeting of chapter facilitators and network volunteers who met to share ideas about better ways to communicate with one another and their members and network survivors. The enthusiasm for being part of SPOHNC and the desire to help others was evident as the discussion investigated ways that the internet could be used to raise awareness and meet the needs of oral and head and neck cancer patients.

Nancy Leupold, President & Founder of SPOHNC, officially opened the conference on Saturday morning, August 19<sup>th</sup>, 2006 with a few brief remarks. She spoke about the first SPOHNC meeting on September 10, 1991 and how she nervously greeted 8 other survivors. She then welcomed the attendees from 23 states and Canada to SPOHNC's 15th Anniversary Conference and Celebration of Life. SPOHNC has come a long way in fifteen years. Nancy then introduced

Dr. James J. Sciubba, past Director of Dental and Oral Medicine at Johns Hopkins Medical Center as the moderator for the day's program.



William Ravich, MD, Diane Saule, MA, CCC-SLP,  
James J. Sciubba, DMD, PhD., Moderator,  
Dorothy Villano, MA, CCC-SLP, speaker

The enthusiasm and need for information was obvious as the audience listened intently to the first guest speakers Dr. William Ravich and Speech Pathologists, Dorothy Villano and Diane Saule addressing topics concerning “Esophageal Dilation” and “Maximizing Swallowing Rehabilitation.” Survivors eagerly submitted questions for the speakers to address. At the conclusion of the presentations

SPOHNC continued on page 4

SPOHNC continued from page 4

and question and answer period, attendees met with exhibitors from major pharmaceutical companies who displayed literature and samples concerning the latest products available for the care of oral and head and neck cancer patients. The representatives were eager to speak with survivors, their families and healthcare professionals and the exhibits were very well attended.



Reconvening following a break with exhibitors

Following the morning break, Dr. Richard Niemtzw, a Colonel with the United States Air Force Medical Corp, addressed the topic of "Acupuncture Treatment for Dry Mouth in Head and Neck Cancer Patients." As xerostomia (dry mouth) is a major problem for oral and head and neck cancer patients who have had radiation therapy, survivors were eager to hear Dr. Niemtzw's presentation and learn of new ways in which to stimulate salivary flow.

Dr. Ann Webster and her presentation, "Mind/Body Medicine: Keys to Survivorship for Cancer Patients" attempted to put all attendees in a relaxed state of mind. She was most successful and people were very interested in learning more about ways to control stress in their lives.

The buffet lunch was a wonderful time for people from many parts of the country to meet and discuss the morning session and to share their own experiences with one another. And soon after, it was time to begin the afternoon program.

Drs David Rosenthal from MD Anderson Cancer Center, Marshall Posner from the Dana Farber Cancer Institute, and Adam Jacobson from Mt. Sinai Medical Center in New York, discussed the "Advances in Treatments for Head and Neck Cancer." Attendees learned of the advances in the options of radiation therapy as well as radioprotection to help improve quality of life. Dr. Posner presented the latest information resulting from the clinical trials related to head and neck cancer and Dr. Jacobson spoke about the advances in surgery and reconstruction showing some of the work being done to improve facial deformities.

Then came the Keynote Speaker, Eva Grayzel, herself a survivor. Her presentation, "Finding Strength From Adversity" was a tremendous success. Through her vivacious personality, survivors and caregivers could identify with each of the steps of her diagnosis and recovery and how her life changed and she "became a better person" for having had cancer. The tremendous response to her presentation came from the heart of cancer survivors and their families.

The final presentation of the day was made by Sally Hart, Esq.,

an attorney with the Arizona Center for Disability Law, in Tucson, Arizona and a consulting counsel to the Center for Medicare Advocacy in Willimantic Connecticut. Her topic, "Medicare Coverage for Dental Care" is a topic of great importance to many head and neck cancer patients as dental issues become more and more of a problem after having had radiation therapy.

Saturday evening a reception was held in honor of the Founding of SPOHNC. Again, survivors, their families and friends, healthcare professionals and exhibitors gathered to enjoy some superb food, some of which was specially prepared for people with eating challenges. The evening was enjoyable and new friendships were made.

The mood changed dramatically on Sunday morning, as the doors to the ballroom of the Marriott Hotel opened to display a festive



atmosphere of burgundy and ivory balloons and flowers. This was a lovely atmosphere in which to hold a "Celebration of Life." The morning began with a banquet buffet breakfast followed by the introduction of the survivor panel and moderator.

Suzanne Frantz, RN, the moderator, who is herself a survivor and Micki Naimoli, Dan Stack, Lillian Corbett and Leonard Lanyo introduced themselves. For a time, it seemed as though this panel and



the attendees of the celebration were one large support group. Questions were proposed by the audience to which the moderator and the members of the panel responded based on their personal experiences. This was truly a wonderful part of the morning's program; one to which everyone; survivor, caregiver, family member, and

healthcare professional could identify.

When most of the questions were addressed, it was time to move on and Nancy Leupold once again introduced Dr. James J. Sciubba, now wearing a different hat, that of the Vice President of SPOHNC. Nancy met Dr. Sciubba more than 15 years ago, when she was first thinking of starting a support group. Without Dr. Sciubba's support and encouragement all these years, SPOHNC would not be what it is today. Even when Dr. Sciubba left Long Island and took a new position at Johns Hopkins, he remained dedicated to helping SPOHNC in any way he could. Nancy introduced Dr. Sciubba to the audience as her very dear friend, her mentor, as well as a dear friend and dedicated doctor to oral and head and neck cancer survivors.

One of America's Favorite Funny Men had our attention as he gave us a good dose of medicinal laughter. He himself a survivor, Norm Crosby entertained us with his play on words and jokes relating to the events of the weekend. Not a somber face was in the audience. He had all of us laughing inside and out like only a funny man can do. Norm Crosby was with us the whole weekend, attending all sessions and mixing in with everyone at the reception. He is a man of kindness and goodwill which was abundantly apparent throughout his contacts with people the entire weekend.

A very special part of the morning program was the recognition of oral and head and neck cancer survivors. Nancy Leupold said a few words about survivorship and then as she asked survivors to stand while special presenters circulated in the ballroom to present a burgundy and a white carnation to each survivor. As all survivors stood with their flowers, there was a feeling of warmth, encouragement and love for all. Nancy then asked that the caregivers stand; the husbands and wives and children and mothers and fathers. These are the unsung heroes of the survivors. The applause was overwhelming.

Nancy then thanked all for helping with the weekend event, including Barry Sebastian, a survivor and volunteer who serves as SPOHNC's Webmaster and the network volunteers and chapter facilitators. Very special recognition was given to Janine Cortese, Network Coordinator of SPOHNC's National Survivor Volunteer Network, and Mary Ann Caputo, Chapter Coordinator and Developer. These two women are an integral part of the SPOHNC team. Nancy then praised her Board of Directors for their support.

And then it was time to say good-bye. Nancy concluded the 15th Anniversary Celebration of Life commenting on how, as cancer

survivors together with our caregivers we journey the long road of recovery trying to present a positive attitude, taking each day at a time, laughing, crying, learning about our disease and often not wanting to accept all we learn. Many of us sought out support from others with similar diagnoses or side effects. Many of us discovered SPOHNC and found comfort and inspiration in talking with others who had "walked in our shoes". We never know what life has in store for us, but it is important, as difficult as it may be, to try and be positive, to hold our heads up high and to make each day count.

SPOHNC's 15th Conference and Celebration of Life is now over, but the comments of this event will stay with us for a long time. Words like "wonderful weekend", "The entire event was extraordinary; The range of information, excellent", "Thank you. Thank you." "Overall excellent program." "Thank you for making this a great event" "Insightful and informative presentations." Thank you for every moment of a memorable weekend." "Program was well done. Trip from California was worth it!" SPOHNC is a wonderful organization!" And a final comment by Barry Sebastian, SPOHNC's webmaster:

"It was indeed a wonderful event. Great speakers, vendors of products for us head and neck patients and survivors. Norm Crosby was hilarious and a great finish to a great weekend. And perhaps the best thing about it was, being in a group of a couple hundred people who knew exactly what it meant to have head and neck cancer. And we all shared similar concerns, side effects, histories, fears, emotional traumas, and social inhibitions. Yes, we know what it feels like to be stared at; to have phantom pains; to have dental problems; to have a stiff neck (literally); to have DRY MOUTH; to have swallowing problems; to take forever to finish a meal; and on and on. These are things we learn to live with every day. But, to be in a room with hundreds of others who can identify with how that feels, and what it means... well, ... I found it to be quite moving. For perhaps the first time in nine years, I wasn't the last one

done eating at a table of friends. AND - I could take my time!"

From Nancy Leupold, Dr. James J. Sciubba, Janine Cortese and Mary Ann Caputo: "To our sponsors, guest speakers, survivors and guests who were able to attend our event and also those who were not present, but sent their support, thank you all so very much. SPOHNC's Anniversary Weekend was truly a weekend of learning, sharing and celebration."

For more information, visit [www.sponhnc.org](http://www.sponhnc.org).



## A TIME FOR SHARING....A Cancer Journey

I will never forget where I was when I got the diagnosis of peri tonsillar cancer. I was in OR room #1 scrubbed on an orthopedic spine case. I am an OR nurse and have worked in the operating room for 22 years. None of that prepared me for the devastating news that I had cancer.

Five days before I had a biopsy of my throat because I had felt enlarged lymph glands on the right side of my neck. The ENT Physician who had done the biopsy knew me well, we worked together in the OR. He did not want to waste any time with starting treatment so he had called me at work to break the devastating news. I felt like someone had dropped a baby grand piano on my head from 3 stories up. Should I cry, continue working as if the person on the other end of the phone had not said what he had said, or just scream? I chose to continue working and that lasted for about 10 minutes when it became clear that I couldn't sustain such composure. I told the circulating nurse the news I had received and that I needed to have someone relieve me. After I was relieved I sat in the lounge thinking over the diagnosis the doctor had given me and what he had told me I needed to do.

My life had changed forever with that short conversation. How could I have head and neck cancer? I had not smoked, I drank a glass of wine with a steak or pasta, a beer with pizza now and again, all of which added up to drinking alcohol every two or 3 weeks. I exercised 3 days a week at the gym, took my vitamins and antioxidants, ate fresh veggies and fruit every day. My husband said I lived on twigs and berries, but I did have a family history of many types of cancer from breast to colon, and I lived with a smoker.

I went home that day to tell my husband the news. I wanted a hug and the statement that we would get through this. I received none of this; instead I got lists off the internet from him about how everything from hair spray to paint had caused my cancer. A hug, kiss and honey I love you never did come. I felt as though I was all alone in this fight. My family and friends were in shock but were there with the physical and emotional support I desperately needed.

I got all the necessary tests and scans, saw my head and neck surgeon and was scheduled for surgery on Friday of the next week. I was

to have surgery then radiation for 7 weeks. Because I was an OR nurse I had assisted my surgeon with several radical neck surgeries so I knew what to expect, but this time it was me, I was the patient. My family was all there the day of the surgery and I needed them. All went well and after a week in the hospital I went home with my drains and trach tube out. I still had the opening into my trachea where my trach tube had been, so to speak I had to cover the opening. The speech therapist had taught me to swallow soft mashed food and liquids. I had lost part of my soft palate that separates the nasal cavity from the mouth and I had some paralysis on the right side of my throat due to nerve damage because of the amount of tissue removed from my throat. A skin graft had been taken from my leg and sewed in the back of my throat to close the defect left by the removal of the tumor. My mandible had been cut to obtain access to the tumor and but back together with a small plate and screws, my chin had a Zorro incision down the center that went under my chin then back to behind my ear continued back down my neck ending just below my collar bone. I was a little scary looking because of the swelling in my face, but I got out and walked everyday to regain my strength.

A port was put into my chest so I could get the medication to protect my salivary glands from the radiation. This medication was administered before the daily radiation treatment. Each day it grew harder for me to swallow and then I could swallow no longer. Unable to take food of liquid I became dehydrated very fast. The decision to put in a feeding tube was made but to keep me hydrated till then I carried around an IV bag of fluid with a pump attached to my port this whole device was concealed in a fanny pack.

The feeding tube called a PEG tube was inserted into my stomach by a gastroenterologist on an out patient basis and I was sent home. The next day cases of liquid feeding was sent to my house. I couldn't begin to feed myself because I had started to vomit the night before so it was off to the hospital to see what was wrong. It was determined that the tube was in the correct position but my stomach just wanted to reject it. I spent the next 4 days in the hospital on medication to stop the vomiting and a pump was attached to

my feeding tube to deliver even measured feedings. I went home to my daughter's house because my husband had refused to quit smoking in the house and essentially rejected me.

Life settled into daily radiation treatments, extreme fatigue, and carrying my trusty tissue box around to spit the copious amounts of foamy saliva I produced. I was unable to work so I took a medical leave. The bright light of my life was my grandsons who accepted me foamy mouth, feeding tube and all. My youngest grandson who was 4 at the time would help me through my feeding by saying "down to the tummy grandma" as I poured the vanilla smelling liquid into my PEG tube.

I returned to work two weeks after my last radiation treatment PEG tube in place and swallowing some food with great difficulty and pain. I had thought that I would be able to eat with less difficulty than this. But I would find again that my expectations were greater than my abilities. I was forced to draw on my nursing and medical knowledge to gain control of my life and redefine what would be normal function for me regarding eating, speaking, drinking, arm and head movement, hearing; all functions I had taken for granted before. Here I was a trained medical professional struggling with this devastating disease, but how great the struggle must be for people without any medical background This thought kept running through my head. I voiced this thought many times to friend in Dallas and my daughter. When I voiced the desire to start a support group for survivors of head and neck cancer they were the first to tell me I should follow through with my vision.

I had found SPOHNC on line while I was staying at my daughter's house. It had given me the help and answers for the problems I was dealing with that my doctor had not. At last someone understood what I was going through I thought. When I marched down to the cancer center in my hospital to present my plan to start a head and neck support group. I knew I wanted it to be part of the SPOHNC organization which had provided me with the answers I needed to keep living my life to the best of my abilities.

Today I co-facilitate a SPOHNC support group that meets once a month. I am blessed to have brought hope and support to many group members to help improve their lives.

SHARING continued on next page

SHARING continued from page 6

Together, we share our struggles and triumphs. I visit patients and their families either before their surgery or after handing out “We Have Walked In Your Shoes” and inviting them to come to our group so they know they are not out there by themselves.

My recovery has had its ups and downs but I am grateful to my supportive family, understanding co-workers and supervisory staff, and the wonderful survivors in my head and neck support group. They have helped me to be the person I am, a cancer survivor and a useful member of society.

Suzanne Frantz  
Clinton Township, MI

**“Tricks of the Trade” What Works For YOU**

Over the years since SPOHNC began publishing its newsletter, people have called, emailed and sent in questions concerning short term and long term side effects related to oral and head and neck cancer and its treatments. At times, we have posed questions in our newsletter and people have responded directly to individuals. At other times, we have responded to questions based on information that we have accumulated from survivors and materials on the Internet or specialists with whom we have contact. But at no time, have we been able to find information related to the many side effects of oral and head and neck cancer and all aspects of the cancer journey in one easy to ready comprehensive booklet.

Consequently, SPOHNC has proposed a project for 2007 that we hope will put valuable information at your fingertips. We are proposing a small spiral booklet that would not only include long and short term side effects of radiation therapy, chemotherapy and surgery and suggestions on how to cope, but would also include information on nutrition and oral supplements, tube feeding information, medical, dental and disability insurance issues, financial support, clinical trials and resources on the Internet.

This is a big project which will take time to develop and it needs your help. You helped us to develop a cookbook which has reached more than 3000 people. You also helped with a questionnaire from which a manuscript is being developed that will be shared with our membership in 2007. A “booklet” like the one described above will be of help to a great

number of people. Just as many of you sent in your recipes and “Tips from the Pros” for our cookbook, we are asking that you send us an email or give us a call or write us a letter concerning problems that you encountered during your cancer journey and how you or your caregiver were able to cope with the problem. This could be as simple as sending us a list of over-the-counter drugs, or the name of prescriptions that helped, oral supplements that you preferred, home remedies that you tried in different situations, exercises that were helpful, etc. Some of you may have found web sites that were especially helpful or books that brought you encouragement during difficult times. We hope to not only include names of products, but also ways in which to get them, including distributor names and phone numbers and Internet addresses.

To do this correctly, we need input from as many of you as possible. Send us your ideas, your suggestions, your concerns and if you know specific information about products, please send that as well.

Just as sharing information in a support group brings new ideas to people struggling with specific problems and oftentimes, helps them in coping with their challenges; sharing information in this project, will bring new ideas and encouragement to all oral and head and neck cancer survivors.

Please take a few minutes and send us an email at [info@spohnc.org](mailto:info@spohnc.org) or call us at 1-800-377-0928 or send a letter to SPOHNC, P.O. Box 53, Locust Valley, NY 11560. Sharing with others can be a great reward for all.

*Thank you for your help!*

Helping to Raise Awareness of Oral and Head and Neck Cancer

**AWARENESS RIBBON PINS**



1-9 pins: \$6.50 each  
10 or more pins: \$6.00 each  
includes shipping and handling

**AWARENESS WRISTBANDS**



**5 for \$10.50**  
includes shipping and handling; Bulk rates available

[www.spohnc.org](http://www.spohnc.org)  
1-800-377-0928

**MEMBERSHIP APPLICATION**

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

Membership includes subscription to nine issues of *News From SPOHNC*

Name \_\_\_\_\_ Phone (\_\_\_\_) \_\_\_\_\_

Address \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Please Check: Survivor \_\_\_ Friend \_\_\_ Health Professional (Specialty) \_\_\_\_\_

**ANNUAL MEMBERSHIP**

- \$25.00 individual
- \$30.00 family
- \$30.00 Foreign (US Currency)

**CONTRIBUTIONS**

- Booster, \$10+
- Donor, \$50+
- Sponsor, \$100+
- Patron, \$500+
- Benefactor, \$1,000+
- Founder, \$5,000+
- Leaders Circle, \$10,000+


Call 1-800-377-0928

to become a member and make a contribution by credit card or order on line at [www.spohnc.org](http://www.spohnc.org)

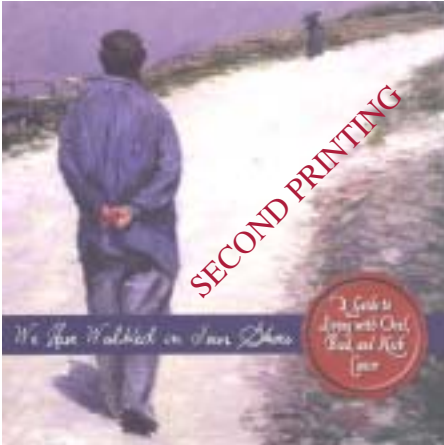
**SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER (SPOHNC)**  
 COORDINATOR/FACILITATOR  
 PHONE

480-512-5604  
 Rachael Kammer, MS, CCC, SLP  
 480-838-5194  
 Bette Denlinger, MA, RN  
 714-445-5707  
 Sabah Qasim, LCSW  
 310-825-5707  
 Jennifer Higgins, MSW  
 760-751-2109  
 Valerie D. Targia  
 403-353-7982  
 Michele Francis, LCSW  
 310-825-5707  
 Virgil Holdridge  
 403-353-3041  
 Joanne Assarson, MSW, LICSW  
 202-444-3755  
 Laura Moon, MSW  
 202-444-3755  
 Lynn Edinoff, LCSW  
 561-737-7733  
 Joseph Bauer  
 941-474-0099  
 Annie Garcia-Montes, LCSW  
 786-596-6951  
 Penny Fisher, MS, RN, CORLN  
 305-243-4952  
 Carmine Pileo  
 941-474-0099  
 Joseph Bauer  
 404-851-5585  
 John Sandidge  
 404-851-5585  
 Ariene Kehir, RN  
 404-778-2369  
 Robyn Egan  
 773-834-2470  
 Marilyn Myles  
 708-327-2061  
 John Groves  
 317-872-6674  
 Janice Leak, MSW, APRN, BC, AOCN  
 410-955-1176  
 Valerie Goldstein  
 617-731-1703  
 Amy Orwig, MSW  
 586-228-2309  
 Suzanne Frantz, RN, CNOR  
 952-545-0200  
 Jill Behnke  
 952-545-0200  
 Carol Murphy, LCSW  
 314-251-6569  
 Doug Steiner  
 406-586-0828  
 Susan Stensland  
 402-559-4420  
 Becky Kopke, RN, BSN, OCN  
 732-923-6473  
 Howard Sakolsky  
 973-586-3522  
 Micki Namoli  
 856-722-5574  
 Sherry Laniado, MSW, LCSW  
 732-557-8279  
 Anita Bryan  
 505-681-1971  
 Fran Tanzeila, RN  
 631-444-7678  
 Jackie Mojica  
 121-844-8775  
 Sandra E. Sabatka, LMSW  
 585-275-4631  
 Nancy Leupold  
 161-759-5333  
 Mark Tenzer  
 914-447-3397  
 Meg Turner  
 704-355-7283  
 Vicki Heinke, LISW  
 614-293-7042  
 Joseph F. Brelsford  
 717-714-8370  
 Dan Stack  
 972-373-9599  
 Jack Mitchell  
 972-496-6561  
 Valerie Oxford, MSSW  
 817-927-6364  
 Linda Tustin, RN  
 281-401-5900  
 Vikki Bravo  
 434-982-4091  
 Corrine Cook, LCSW  
 703-776-2813  
 Rachael Kammer, MS, CCC, SLP  
 608-263-4896

WISCONSIN-MADISON (new)  
 VIRGINIA-FAIRFAX-Heads Up!  
 VIRGINIA-CHARLOTTEVILLE  
 TEXAS-HOUSTON/TOMBALL  
 TEXAS-FORT WORTH (new)  
 TEXAS-DALLAS  
 TEXAS-DALLAS  
 PENNSYLVANIA-MECHAMCIBURG  
 OHIO-COLUMBUS  
 NORTH CAROLINA-CHARLOTTE  
 NEW YORK-WESTCHESTER  
 NEW YORK-SYOSSET  
 NEW YORK-ROCHESTER (new)  
 NEW YORK-MANHATTAN  
 NEW YORK-LONG ISLAND EAST  
 NEW MEXICO-ALBUQUERQUE  
 NEW JERSEY-TOMS RIVER  
 NEW JERSEY-PENNSYLVANIA  
 NEW JERSEY-MORRISTOWN  
 NEW JERSEY-LONG BRANCH (new)  
 NEBRASKA-OMAHA  
 MONTANA-BOZEMAN (new)  
 MISSOURI-ST LOUIS (new)  
 MINNESOTA-MINNEAPOLIS (new)  
 MICHIGAN-TROY  
 MICHIGAN-DETROIT-HFHS  
 MASSACHUSETTS-BOSTON  
 MARYLAND-BALTIMORE-JHMI  
 ILLINOIS-MAYWOOD  
 ILLINOIS-CHICAGO  
 GEORGIA-ATLANTA-Emory  
 GEORGIA-ATLANTA-Emory  
 FLORIDA-SARASOTA (new)  
 FLORIDA-PALM BEACH  
 FLORIDA-MIAMI-Mont Silverblatt Head and Neck  
 FLORIDA-MIAMI  
 FLORIDA-GAINESVILLE  
 FLORIDA-ENGLEWOOD (new)  
 FLORIDA-BOYNTON BEACH  
 FLORIDA-BOCA RATON  
 DC-WASHINGTON-LCC  
 COLORADO-DENVER  
 CALIFORNIA-SAN FRANCISCO-UCSF  
 CALIFORNIA-SAN DIEGO  
 CALIFORNIA-ORANGE-UCL  
 CALIFORNIA-LOS ANGELES-UCLA  
 ARIZONA-SCOTTSDALE  
 ARIZONA-PHOENIX  
 SPOHNC CHAPTER

  
**SUPPORT FOR PEOPLE WITH  
 ORAL AND HEAD AND NECK CANCER**  
**S•P•O•H•N•C, Inc.**  
 P. O. Box 53  
 LOCUST VALLEY, NY 11560-0053

NON-PROFIT  
 ORGANIZATION  
 U.S. POSTAGE  
 PAID  
 LOCUST VALLEY, NY  
 PERMIT NO. 28



*“We Have Walked In Your Shoes,  
 A Resource Guide to Living with  
 Oral, Head and Neck Cancer”*  
 Visit us at [www.spoHnc.org](http://www.spoHnc.org)