

## CHEMOTHERAPY IN THE TREATMENT OF HEAD AND NECK SQUAMOUS CELL CANCER: UPDATE 2006, PART II

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### Treatment of Recurrent And/Or Metastatic Disease

Locoregionally recurrent HNSCC refers to disease that has come back to the head and neck area and is limited to areas above the collarbone. In this situation, surgery and/or radiation may be employed with curative intent, with selected patients being rendered disease-free long term. The likelihood of success will vary depending on a variety of factors, such as the extent of disease at relapse (smaller, primary site disease only without neck node involvement is better prognostically) and the time interval since prior treatment (a longer interval is better). Historically, radiation could not be performed in an area that had previously been irradiated. However, with newer techniques like Intensity Modulated Radiation Therapy (IMRT) that allow better targeting and dosing of the radiation beam, re-irradiation may be an option for recurrent disease in a prior radiation field, and frequently concurrent chemotherapy is incorporated. With such an approach, a selected minority of patients with inoperable disease will be controlled long term. Proper patient selection is of central importance, because toxicity may be increased with this approach and for many patients chemotherapy/re-irradiation will offer no significant advantage compared to chemotherapy alone. The relative effectiveness of chemotherapy alone versus concurrent chemotherapy/radiation in this setting is under investigation.

If neither surgery nor radiation is feasible for new locoregional

relapse, or if the cancer has metastasized to other body regions, then the prognosis is more worrisome. Selected patients may benefit from resection of a distant metastatic site, particularly if limited to the lung, but chemotherapy alone is often used in this situation, with the goals of treatment being prolongation of life and improvement in symptoms/quality of life. Cure is rare after treatment with chemotherapy alone in this setting, and the median survival among patients for whom chemotherapy alone is the main treatment option is less than one year.

### Standard Chemotherapy

Active agents for HNSCC include but are not limited to methotrexate, cisplatin, carboplatin, 5-fluorouracil, paclitaxel, docetaxel, and bleomycin. Different mechanisms of action are involved. Anticipated major response rates when a single drug is used are approximately 20%, with a median duration of response measured in weeks to months. Using a combination of drugs will double the major response rate. However, toxicity is increased, the durability of the responses remains disappointing, and randomized trials to date have not convincingly demonstrated an improvement in survival compared to treatment with one drug alone. Nasopharynx cancers on average are somewhat more responsive to chemotherapy than the other sites of head and neck cancer. Furthermore, gemcitabine is a particularly active drug for nasopharynx tumors, although its activity for squamous cell cancer at other head and neck primary sites is more modest.

Given the disappointing efficacy of drugs like the ones listed above for HNSCC in the recurrent and/or metastatic setting, participation in a clinical trial is often a good option for a patient. There is much research that is ongoing to identify new agents, including ones that look to exploit newly identified targets and offer the hope of treatment that is more specific to the tumor and less toxic to non-malignant tissue and to the patient – so called “targeted therapies.” There are many potential targets. The Epidermal Growth Factor Receptor (EGFR) and related pathways as well as angiogenesis (new blood vessel formation) are among the most high profile right now.

### Targeted Therapy

#### Targeting the EGFR and Related Pathways

There has been particularly keen interest in agents that target the EGFR and the related signaling pathways. EGFR is highly expressed in the majority of HNSCC, and its presence is inversely related to prognosis. Cetuximab, gefitinib, and erlotinib are examples of agents that are commercially available and target EGFR. Cetuximab, a monoclonal antibody that is administered intravenously, binds to EGFR on the outer surface of cancer

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COMING IN MARCH 2007  
“The Impact Of Head And Neck Reconstruction On  
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cells. Gefitinib and erlotinib, administered as pills by mouth, are both small molecules that bind to the signaling portion of EGFR (the “tyrosine kinase domain”) inside cancer cells. Of these agents, only cetuximab is FDA approved for use in HNSCC (concurrent with radiation for locoregionally advanced disease; in platinum-refractory patients with recurrent and/or metastatic disease).

Rash is a common side effects of all these agents and appears to be associated with improved response. There is as of yet no good molecular marker of response in HNSCC. Although these drugs have activity in HNSCC, objective response rates are modest (4% to 13%). Disease stabilization occurs in a higher percentage (43% to 53%), however, median survivals remain less than a year (6 to 8 months). The efficacies of all these agents compared to more traditional chemotherapy drugs has not been well assessed. There is keen interest in obtaining a better understanding of how resistance to these agents occurs, and the development of combination therapy including such agents intended to overcome drug resistance.

Cetuximab has been the most investigated of these agents in HNSCC. Although there is theoretical synergy with chemotherapy, in patients with unresponsive disease, response rates appear similar whether cetuximab is given alone or with the drug to which the tumor is not responding. Of note, a randomized trial done through the Eastern Cooperative Oncology Group (ECOG) compared cisplatin plus cetuximab versus cisplatin plus placebo in patients with recurrent and/or metastatic HNSCC that was less heavily pretreated. The incorporation of cetuximab under these more prognostically favorable circumstances lead to a significant improvement in the major shrinkage rate (26% versus 10%). This response advantage did not translate into a significant survival improvement, although the study was relatively small to more definitively address a survival endpoint. A larger study addressing a similar question is in progress in Europe. Until more data becomes available, chemotherapy combined with cetuximab in this setting is best pursued within the context of a clinical trial.

Targeting the Vascular Endothelial Growth Factor (VEGF)

VEGF is responsible for the induction of angiogenesis that allows tumor growth. VEGF is frequently elevated in HNSCC, and elevated VEGF expression has been associated with a poor prognosis. As was the case with EGFR, there are different ways to interrupt the impact of VEGF. There is limited data available in HNSCC regarding the agents designed to impact upon angiogenesis at this time.

Bevacizumab is probably the best known anti-angiogenic agent. It is an antibody against a potent subtype of VEGF. Its use when combined with chemotherapy is associated with improved response rate and survival outcomes compared to treatment with chemotherapy alone in patients with breast, colorectal, and nonsmall cell lung cancers. In squamous cell non-small cell lung cancer, tumor hemorrhage, preceded by the development of a cavity within the tumor, was observed, consistent with significant anti-tumor effect. Bevacizumab interferes with wound healing. Bevacizumab may be associated with elevated blood pressure and protein in the urine, although these side effects are usually mild. More severe, albeit uncommon side effects, include the development of blood

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clots, severely elevated blood pressure, and perforation of the digestive tract.

As noted above, only preliminary data are available regarding the efficacy of bevacizumab with chemotherapy or radiation in HNSCC. Until more data becomes available, use of this agent in the management of HNSCC is best pursued within the context of a clinical trial.

Summary

The role of chemotherapy in the treatment of HNSCC has evolved considerably over the last twenty years. The changes have been particularly dramatic among patients with local and/or regionally advanced disease, where chemotherapy figures prominently in the management of unresectable disease, nasopharynx cancer, organ preservation programs, and the poor risk adjuvant setting. Our growing understanding of HNSCC at the molecular level is paying dividends as new targets and related drugs are identified. The recent FDA approval of cetuximab for use in two different settings, illustrates the type of bench to bedside collaboration between basic science and clinical investigators that we anticipate will occur increasingly in the years ahead. Well done clinical trials are a fundamental part of this process, and greatly assist in determining when and how to optimally use chemotherapy to improve disease control outcomes. These studies are often an excellent treatment option for patients, and deserve our support.

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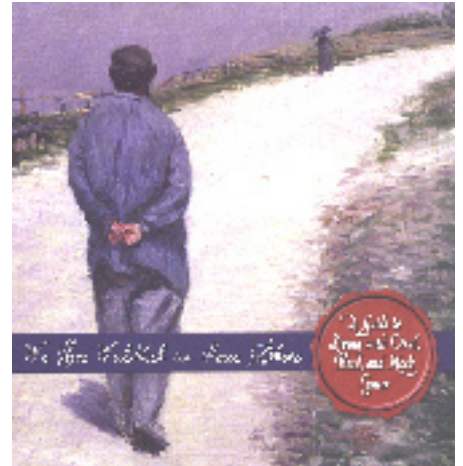
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## Rapid Acupuncture Treatment for Severe Dry Mouth Secondary to Radiotherapy for Head and Neck Cancer Patients

RICHARD C. NIEMTZOW, MD, PHD, MPH

**D**ry mouth or xerostomia is a common complaint for head and neck cancer patients following radiotherapy, chemotherapy and surgery. This unfortunate condition of the mouth is a result of destruction and /or significant biological damage to the salivary cells that compose the three major salivary glands and the accessory salivary glands anatomically found in the head and neck area. This discussion will be limited to the major salivary glands.

There are 3 major salivary glands: the parotid glands which we have on each side of our face, the 2 mandibular glands found under the tongue area, and the 2 sublingual glands found in the floor of the mouth. The parotid glands secrete watery saliva called serous fluid. The mandibular glands secrete a mixture of serous and mucus fluids. The sublingual glands secrete mostly a mucous fluid. The saliva itself is somewhat of an alkaline fluid which moistens, softens, and aids in digestion. The parotid glands secrete enzymes, called amylases, which are very important in the first steps of carbohydrate digestion. The incidence of stomach ulcers is higher in patients having dry mouth because of a lack of these enzymes. A deficiency of saliva will result in periodontal disease; the patient will experience an excessive increase in caries and gum irritation because of reduced saliva washing and lubrication of the tissues<sup>1</sup>.

Salivary glands are composed of cells that are very specific to the function of saliva. The mucous cells are generally responsible for the thicker and sticky characteristic of the saliva and are generally contained in the mandibular and sublingual glands. The serous cells are characterized by a watery fluid-like saliva as produced by the parotid glands. The mucous cells are more resistant to both radiation and chemotherapy than the serous cells. This latter population is probably injured and destroyed more quickly than the mucous cells. What this means for the patient is a thick, sticky and ropy saliva during the course of/or at the completion of radiotherapy and/or chemotherapy<sup>2,3</sup>.

When a patient undergoes the various therapeutic modalities of radiation therapy, chemotherapy, and surgery, the salivary glands

are damaged and destroyed which, for all practical purposes, does not lend itself to the comfort and well being of the patient<sup>3</sup>.

The purpose of the radiation is to destroy the cancer cells. Various techniques in radiation oncology are used to target the tumor, but to spare the normal tissues. These techniques may consist of fractionation techniques, such as hyper fractionation, intensity modulated radiation, and three-dimensional conformal radiation. Unfortunately, no matter what techniques are used to spare normal tissue, the salivary glands may be destroyed or damaged to a certain extent. This translates into a low saliva output or no saliva whatsoever. Some patients are administered a radiation protective agent or stimulating drug to counter the effects of the radiation to the saliva glands<sup>3</sup>.

The chemotherapy used in head and neck cancer patients has similar goals to that of radiation therapy: destroy the cancer. Unfortunately, chemotherapy can not differentiate between tumor cells and normal cells. Because the chemotherapy circulates through the vascular system, it will be detrimental to the salivary glands, producing destruction and damage of the cells that are responsible for producing saliva. In a similar fashion to radiation, this translates into either no saliva output or reduced saliva output<sup>3</sup>.

Surgical removal of the tumor(s) and lymph nodes can disturb the circulatory hemodynamics and the nerves that are responsible for salivary secretion. In some cases, it is necessary to remove some of the salivary glands. Hence, an additional detrimental impact on saliva further adding to the discomfort of the patient<sup>3</sup>.

Consequently radiotherapy, chemotherapy and surgery therapies impact the functioning of the salivary glands to the disadvantage of the patient's comfort. This is certainly acceptable when survival is the primary concern of the patient and, thus, dry mouth becomes an "acceptable side-effect" of the cancer treatments.

In many case, it appears that the radiation /chemotherapy has turned off a mechanism which is most likely integrated into the parasympathetic system that may stimulate and control the salivary glands. The acupuncture

technique that I developed appears to re-establish the neurological pathway or component responsible for salivary glands stimulation. And because the acupuncture causes saliva to be secreted in many cases within 10 minutes, it must be obvious that some injured salivary gland cells are still functional. In the majority of cases, this saliva output is reduced, but maintained for months and years, varying from individual to individual. Many patients have communicated that the acupuncture improves their quality-of-life and is superior to conventional drugs and treatments.

Certainly, there are many proposed acupuncture treatments for dry mouth. However, in this article, the acupuncture protocol to help overcome xerostomia (dry mouth) as a result of post-radiation, chemotherapy, and surgery is the one that was developed by Dr. Peter A. Johnson and myself at the Naval Medical Center in San Diego, California in November of 1999. The results of this small study were presented at the American Academy of Medical Acupuncture (AAMA) Symposium in June 2000 and showed there were no adverse effects referable to acupuncture and that an increased degree of salivation was subjectively present in all cases after acupuncture. Follow-up evaluations revealed that the oral buccal mucosa was moist and that saliva was present. All patients were capable of expectoration. Interestingly enough, this protocol involved a two step procedure employing acupuncture. In the first phase, acupuncture needles were placed in the ears and the index fingers. If no saliva was forth coming in 45 minutes, the needles were removed and electrical stimulation was applied to the ear on points historically designated for salivary secretion. With further refinement of the technique it was possible to produce saliva with a total of 8 needles (6 in the ear and 2 in the fingers). The results were very encouraging and we went on to do another clinical trial involving about 50 patients. The current protocol delineates various needles on the index finger that help stimulate a higher ratio of serous cells to mucous cells with the result being a saliva that is more fluid. The previous protocol in 1999 produced a thick and sticky saliva. Apparently the positioning of

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ACUPUNCTURE continued from page 6  
the needles more distal on the index finger and not on known acupuncture points, but still on the acupuncture meridian had a rheostat effect. This is like the electrical rheostat that is used to brighten or dim lights in our homes,

The current protocol has been very helpful to patients. After continuing extensive research and observation, it has been determined that the protocol can now be performed in 2 sessions separated by 24 hours. It appears that the saliva secretion peaks on the 2nd treatment. This is performed by placing needles in very specific locations in both the ears and the index fingers. Further treatments are rarely necessary. There is a very small percentage of patients who will not obtain the 6 months to several years of saliva flow after the 2 acupuncture treatments. For these patients, repeat treatments will be necessary. Unfortunately, it is difficult to predict the small percentage that will have a very short remission. There is no benefit performing this treatment concurrent to radiotherapy. It is very inconvenient and offers no advantage. Also, acupuncture for saliva flow during radiation does not offer any protection whatsoever to salivary production<sup>3,4,5,6</sup>

A typical treatment will produce an increase in saliva in about 10 minutes. On the 2nd day of treatment, the salivary secretion occurs faster and is more abundant. A patient who does not receive the 2nd treatment within 24 hours is at a disadvantage. This is a critical step in the protocol. Waiting longer than 24 hours for the 2nd treatment has diminishing returns.

This acupuncture protocol may be helpful to many patients with dry mouth as a result of head and neck cancer therapies. I am committed to continuously improving this technique and communicating this information.

Patients may ask, "In what way will this protocol improve?" Soon there will be a new modification to the protocol that may be beneficial in helping to improve restoration of *taste*. Several patients have reported encouraging results. This information will be available to clinicians in the near future.

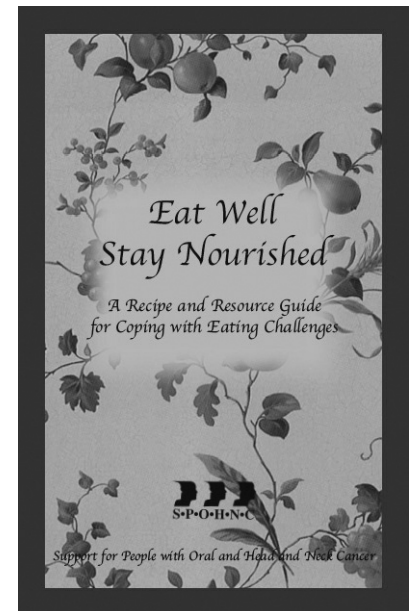
The practice of acupuncture may slowly if ever, find its way into the radiation oncology clinic. It may take clinical trials to convince professionals of its usefulness though there is nothing wrong about healthy skepticism. But, the fact that patients are successfully being treated and reporting a substantial benefit suggests that this modality is a step in the

right direction. The vast majority of patients presently being treated with this particular protocol is a result of word-of-mouth and self-referrals. I think it is very important to evaluate this technique as technology. Eventually other stimulating devices will take the place of needles. We are already seeing miniature self-contained probes that remain in the ear operated by battery. These probes provide constant stimulation to the ear acupuncture points over a very long period of time. This is just the beginning of future technology that will be applied to the problem of xerostomia. Perhaps in the near future, acupuncture, which is more than 5000 years old, may become one of the most modern treatments for head and neck cancer patients suffering from xerostomia,

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#### REFERENCES

1. <http://www.salivary-glands-disease.com/>
2. <http://arbl.cvms.colostate.edu/hbooks/pathphys/digestion/pregastric/salivary.html>
3. Niemtow, Richard C. MD, PHD, MPH, Lecture: Acupuncture Treatment for Dry mouth in Head and Neck Cancer Patients, Presented: Support For People With Oral And Head And Neck Cancer (SPOHNC), 15<sup>th</sup> Anniversary Conference and Celebration of Life, Marriott LaGuardia Hotel, New York, August 19, 2006.
4. Niemtow RC. "Acupuncture Technique for Pilocarpine-Resistant Xerostomia Following Radiotherapy for Head and Neck Malignancies". Presented at the American Academy of Medical Acupuncture Annual Symposium, Orlando, Florida, Apr 2000.
5. Niemtow RC, Peng YP, May BC, Inouye WS, Johnstone PAS. "Acupuncture Technique for Pilocarpine-Resistant Xerostomia Following Radiotherapy for Head and Neck Malignancies". *Medical Acupuncture*. 2000; Vol 12, No 1.
6. Johnson, Peter A., MD , Peng, Y. Peter, MD, May, Bryon C. MD, Inouye, Warren, S., MD and Niemtow, Richard C., MD, PHD, MPH, "Acupuncture For Pilocarpine-Resistant Xerostomia Following Radiotherapy for Head and Neck Malignancies", *Int. J. Radiation Oncology Bio. Phys.*, Vol. 50, No 2. pp 353-357, 2001.



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## A TIME FOR SHARING... HOW I TAUGHT MYSELF TO EAT (With a Lot of Help)

I was a healthy woman on December 4, 2000. I had my annual physical by my physician of 26 years and it was, as usual, very thorough. My doctor's only concern was for my weight. I was not obese, but I weighed about 25 pounds more than I should and even at nearly six feet tall I was uncomfortable and once again vowed to lose that frustrating 25 pounds.

But on the morning of December 5, I felt two small lumps on the left side of my neck, under my chin. I never had lumps on my neck, I was in perfect health, and it just didn't seem right. I needed to see my doctor again.

I saw the on-call doctor, who assured me cancer doesn't appear overnight. But when I saw my own doctor, a week later, she was concerned enough to send me to a surgeon for a needle aspiration.

The results of the aspiration were inconclusive, and the surgeon also assured me that cancer doesn't appear over night. I had no other symptoms. I felt fine; I was not coming down with anything, as the other doctors suggested. Something was wrong.

I was living in New Hampshire at the time and in a low residency graduate writing program in Vermont. I left for Vermont after Christmas and over the two week residency my swollen lymph nodes grew, one to the size of a small egg. Another lymph node began to swell on the right side of my neck.

When I returned to New Hampshire, my doctor made an appointment to see the surgeon again, this time to have a node removed and biopsied. On February 2, 2001, she called me to come to her office, and bring my husband, Dick. She told us I had bilateral neck cancer and it didn't look good. She made an appointment for me to see an ENT on Monday morning.

I knew my own body, and my doctor trusted me. Instead of being afraid, I was confident my own good health would see me through this. I was the only one who wasn't worried.

The ENT in New Hampshire couldn't find anything wrong with my throat, and he referred me to a doctor in Massachusetts. After being poked, prodded, grammed, scanned, and ultrasounded, the ENT said I had an occult cancer, one with no primary site, that due to

the nature of the cells and site of the cancerous lymph nodes, was neck cancer. He referred me to a radiation oncologist and a medical oncologist. And still I thought I would beat it. The lumps on the left side of my neck were growing larger.

After examining every option on the menu, I decided on radiation as a first course followed by the second course, surgery. I was saving chemotherapy for a last effort, or an unwanted dessert. This was a chance to lose those pesky 25 pounds.

My ENT scheduled me for a punch biopsy of my throat in order to find the possible site of my cancer. The only result was an extremely sore throat and a recommendation for a feeding tube.

Instead of eating everything as I had been ordered, I was cutting back on food. I wanted to start the Cancer Diet early, and in retrospect, I should have been eating everything in sight. I should have had hamburgers and pizza and candy, I should have been eating Italian food and Mexican food and anything hot and spicy.

I thought the feeding tube was going to be temporary. I didn't realize I was going to be on it for two years.

When I was half-way through the radiation, I went to the hospital with radiation crash. I had everything: severe mucositis, pneumonia, ulcers, dehydration, bad blood, thrush. I don't remember anything about the trip to the hospital or the first few days, but when I left the hospital I had lost 25 pounds. The Cancer Diet was working, but I wasn't liking it, and I was feeling much too mortal for comfort. I went home with a machine that put me on the feeding tube full time.

In June I had a modified radical neck dissection on the left side. My ENT wanted to do both sides but with support from my Rad/Onc, I negotiated for just one side. If the cancer wasn't dead, he could do the other side, but I was only ready for one at a time. On June 12, the cancer was dead and I was officially declared in remission. The surgical residents who assisted my ENT cheerily told me I was a Stage 4 and probably wouldn't live to see the end of 2001. I might be Stage 4, I replied, but I certainly was going to live. I had things I

needed to do: I had to see my daughter get married; I wanted to go to China, the Red Sox had yet to win the World Series, and I wanted to see the next season of *The Sopranos* and no cancer was going to get in the way of that.

I barely finished the second semester of grad school and going to the residency in June was out of the question. When I finished radiation, I totally ruled out chemotherapy. The treatment that was supposed to cure me seemed to be killing me and I was so tired I went to bed with my cat Larry and an obsession for watching the Food Network.

I really intended to be the fun cancer patient who cheerfully took her predicament in stride; after my demise people would say of me "Oh, she never lost her marvelous sense of humor; she did so much in her short time; she kept her positive outlook on life and no one would ever know she was sick" Instead, I was the kind of patient who threw up constantly, spit like a teenage boy, fainted at peculiar moments, slept all day, and spoke with a smoky, whisky voice that sounded like a very old man.

I stopped taking pills by mouth and began to crush them up and send them through the feeding tube, which I regarded as an interloper who had taken over my life. Every night I threw up six to eight times while my patient husband stood next to me. The only thing I was taking orally was diet ginger ale. I wasn't going to allow any extra calories in even if they were going out every evening.

Due to a chyle leak in my dissected left neck the doctor inserted a PIC line in my right arm and put me on intravenous feedings. Chyle is a milky white, fatty lymphatic fluid that had no place to go except into my shoulder. I left the hospital after a ten day stay with drainage bulb hanging from my neck and tubes hanging from my arm. I needed a diet with no fat in order to stop the leak; after a month, the PIC line was finally removed.

In September, I stopped throwing up and went back to work part time. I dropped from a size 14-16 to a size 6 and still didn't have the sense to know it was wrong. I had been told to look on the positive side of cancer and for me, it was finally getting the body of a runway model; but a model with an asymmetrical neck.

SURVIVOR continued on page 5

SURVIVOR continued from page 4

In late fall, I took my daughter and her bridesmaids out for lunch. It was the first time I had been in a restaurant since my diagnosis. I sat with my glass of water with no ice, watching the girls enthusiastically eating hamburgers, hot chicken wings, roast beef sandwiches, and chicken Caesar salads, I realized how much eating is a part of social life. I sat and immersed myself in the senses of a restaurant: the sounds of dishes clattering, utensils scraped across plates, the smells of the food, the talk and laughter of the patrons. I watched as the girls bit into their food and chewed and swallowed. I realized the enormity of not being able to eat, and I wanted even more to eat again.

I did return to grad school for the December semester, complete with cases of tube food. I tried to eat but whatever I ate I later blew out my nose. I hated the tube that was keeping me alive, regarding it as an unpleasant reminder that I wasn't better than everyone else who had cancer. I needed to get rid of it and it became my mission to teach myself to eat.

My daughter married in June, 2002. I still couldn't eat. I had crab bisque that I later blew out my nose. I called a cancer support line and for the first time, I spoke to someone who had cancer just like I did. He told me to go to swallowing therapy. As wonderful as my doctors were, they never suggested swallowing therapy. By the end of the week, my primary care physician had me working with a speech pathologist.

For the next few months, I practiced my exercises. I pushed my tongue against a spoon and tried sticking my tongue out and moving it from left to right. I shouted "K-K-K-K-K-" as emphatically as I could and I did my exercises constantly. I drove around my small town with my lips pursed in an O or a stupid grin on my face as I tried to exercise my facial muscles. Instead of singing along to the radio, I yelled "E-E-E" in a sing-songy voice. If my therapist had suggested it, I would have tied a concrete block to my tongue and tried to lift it.

I had barium swallow after barium swallow and the progress was slow. After each test the orders were "NPO"—nothing by mouth. I gave up diet ginger ale and switched to diet Coke and I practiced swallowing hard.

I had acupuncture to bring back my saliva, and I chewed gum for the first time in a year and a half, but the effects didn't last.

In late September my ENT referred me to a course of hyperbaric oxygen therapy to see if it would increase the blood flow through my jaw and help my raw throat to heal. I spent my mornings like Snow White in a glass coffin, watching Food TV through the glass and dreaming of Molto Mario cooking Italian food for me. When I drove home I practiced my exercises, screaming "-e-e-e" like a woman possessed.

In November I went on a 10-day western Mediterranean cruise with five women friends. Off the ship, I ate crème Brulee. On the ship I tried to eat everything, at least a bite of everything. I had hauled all my tube food with me and it was sitting in my closet but I was determined to eat. I finally could swallow small bites of food without choking or sneezing it out. I was on the road to eating on my own.

*"I might be Stage 4....but I certainly was going to live. I had things I needed to do: I had to see my daughter get married; I wanted to go to China, the Red Sox had yet to win the World Series, and I wanted to see the next season of The Sopranos and no cancer was going to get in the way of that."*

When I returned to grad school in December 2002 for my final semester, I didn't bring my tube food with me. I was going to show the doctors that I could maintain my weight without the cans. By then I was a size 2-4 and even I was beginning to think I was slim enough. Dick said it was like sleeping with a wire coat hanger. I was going to weigh-ins at the doctor's office and I was the first patient she ever had who said the scale was weighing too light, rather than too heavy. I wanted the tube out in January to celebrate my fiftieth birthday and my semester-late graduation.

In February the doctor yanked the tube out. It was the best pain I had in the last two years.

Since then I have improved my eating to the point where I have gained much of the weight back. I still have extreme xerostomia and trismus, which makes eating difficult. My

ability to taste is still impaired. What tasted good before tastes terrible and things I hated before, like eggs, have become my favorite food. The lack of saliva and sensitivity in my mouth makes it impossible to eat the foods I should have been eating when I began radiation. No more hot and spicy, no more bread. I'm often uncomfortable eating in front of other people because I still occasionally have coughing fits and the way I eat and what I eat looks strange to those who don't know my background. But I do eat with other people; I do go to restaurants; and I no longer feel like I'm looking in from the outside. Even with my limited diet I'm back in society.

Dick retired in April, 2003 and in October we moved to Florida (so I could be warmer) and to a fly-in community where Dick could keep his airplane. My eating problems have never kept us from traveling; just as my cans of liquid never kept me home.

In October, 2005 my husband and I went on my dream trip, to China and Hong Kong, for 14 days. I've been to Hong Kong many times but had never been to China. Most days there was plenty for me to eat, except one day when all I ate was bean sprouts. Everything that tasted good to me tasted good to everyone else at the table and sometimes the food was gone before I had a chance at it. But I ate easily with chop sticks, more easily than eating with a knife and fork.

Because of my aggressive tooth care, I've had few problems with my teeth. My dentist says my mouth is healthier than that of most of his other, non-cancer patients. I still struggle with the lack of saliva and limited motion of my jaw. But my quality of life has greatly improved. I have my sense of humor back and my positive outlook on life. In June I reached my five-year mark of remission.

Larry and I still watch cooking shows but not all the food is denied me anymore. My dear, patient husband sits with me as I struggle to chew and swallow, even when he is long finished. I eat out in public more, though I usually bring home a take away container because I can't eat fast. I have a new set of goals to look forward to.

I'm glad that I was able to teach myself to eat.

*Peach Gazda*  
Port Orange, FL



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Keri Winchester, MS, CCC-SLP 480-512-5604  
Keri.Winchester@bannerhealth.com

**ARIZONA-SCOTTSDALE**  
Virginia G. Piper CA Center  
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Bette Denlinger, MA, RN--480-838-5194  
betmeldenlin@cs.com  
Sally Kaszilek  
skaszilek@yahoo.com

**ARKANSAS-NORTHWEST**  
NWA Cancer Support Home  
3rd Saturday, 10:00 AM-12:00  
Jack Igleburger--479-876-1051/586-4807  
tmplnjak@cox.net

**CALIFORNIA-LOS ANGELES-UCLA**  
UCLA Med. Pla., Rad/Onc Conf. Rm. B-265  
1st Tuesday, 6:30-8:00 PM  
Sabah Akmal, LCSW--310-825-5707  
sakmal@mednet.ucla.edu  
Pam Hoff, LCSW--310-825-6134  
phoff@mednet.ucla.edu

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Jennifer Higgins, MSW--714-456-5235  
jhiggins@uci.edu

**CALIFORNIA-SAN DIEGO**  
Valerie Targia--760-751-2109  
valtargia@yahoo.com

**COLORADO-DENVER**  
Porter's Adventist Hospital  
Last Thursday, 6:30-8:00 PM.  
Virgil Holdridge--303-798-3041  
virgil126@juno.com  
Jeanie Curry--303-778-5832

**DC-WASHINGTON**  
Lombardi Cancer Center.  
3rd Monday, 12:15-1:45 PM  
Joanne Assarsson, MSW, LICSW 202-444-3755  
assarssj@gunet.georgetown.edu

**FLORIDA—BOCA RATON**  
Boca Raton Community Hospital.  
1st Tuesday, 4:00-5:00 PM  
Laura Moon, MSW--561-955-5897  
lmoon@brch.com

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3rd Thursday, 10:30-12:00 PM  
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Carol Glavin, MSW, LCSW--352-371-86  
CGlavin@gru.net  
No calls after 9:00 PM, please

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1st Wednesday, 5:30 PM  
Annie Garcia-Montes--786-596-6951  
anniegm@baptisthealth.net

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pfisher@med.miami.edu  
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mashmarty@hotmail.com

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hope@wellness-swfl.org

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cptess453@aol.com

**GEORGIA-ATLANTA**  
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johnsandidge@msn.com

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Arlene.Kehir@emoryhealthcare.org

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Robyn Egan--773-834-2470  
regan@medicine.bsd.uchicago.edu

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Marilyn Myles--708-327-2061  
mmyles@lumc.edu

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Jgroves14@comcast.net

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317-782-7604  
Janice.Leak@ssfhs.org

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mmoody@kumc.edu

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Amy Orwig, MSW--313-916-7578  
aorwig1@hfhs.org

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sfrantz@beaumont-hospitals.com

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nancydoug@theglobal.net  
Wendy Gwinner, LCSW--406-585-5070  
wgwinner@bdh-boz.com

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Terri Painchaud--704-364-7119  
Trappi6@yahoo.com

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Susan Stensland-- 402-559-4420  
sstensland@nebraskamed.com

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NEW JERSEY-TOMS RIVER  
Community Medical Center  
Last Thursday, 3:00 PM  
Sherry Laniado, MSW, LCSW--732-557-8270  
slaniado@sbhcs.com

NEW MEXICO-ALBUQUERQUE  
Christ Unity Church  
3rd Friday, 4:30-5:30 PM  
Anita Bryan--505-681-1971  
anitabeach2@yahoo.com

NEW YORK-LONG ISLAND  
Dennis Staropoli--631-682-7103  
1st. Wednesday, 7:30-9:00 PM  
Dennis Staropoli--631-682-7103  
Den.star@hotmail.com

NEW YORK-MANHATTAN  
Beth Israel Head and Neck Institute  
4th Tuesday, 1:30-3:30 PM  
Jackie Mojica--212-844-8775  
jmojica@chnpnet.org

NEW YORK-ROCHESTER  
Strong Memorial Hospital  
1st. Thursday, 4:00-5:30 PM  
Sandra E. Sabatka, LMSW--585-275-4631  
Sandra\_Sabatka@URMC.Rochester.edu

NEW YORK-SYOSSET  
NSLIJ-Syosset Hospital  
2nd Thursday, 7:30-9:00 PM  
Nancy Leupold--516-759-5333  
nleupold@spohnc.org

NEW YORK-WESTCHESTER  
White Plains Hospital Cancer Center  
2nd Thursday, 7:00 PM  
Mark Tenzer--914-472-3397  
tenzer1@optonline.net

OHIO-COLUMBUS  
The James Cancer Hospital &  
Solove Research Institute  
1st. Monday, 3:30-5:30 PM  
Vicki Heinke, LISW--614-293-7042  
Vicki.Heinke@osumc.edu

OKLAHOMA-TULSA  
Hardesty Public Library  
1st. Tuesday, 6:30 PM  
Christine B. Griffin, RN--918-261-8858  
Beritgriffin@cox.net

PENNSYLVANIA-MECHANICSBURG  
Health South Lab  
Every 3rd. Month/3rd. Tues., 6:30 PM  
Joseph F. Brelsford--714-774-8370  
Jfbrelsford1@mmm.com

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TEXAS-DALLAS  
Baylor Irving-Coppell Medical Center  
2nd Saturday, 10:00 AM  
Dan Stack--972-373-9599  
danstack@aol.com

TEXAS-DALLAS  
Cvetko Ctr. at Sammons Cancer Ctr.  
2nd Tuesday, 11:00 AM-12:30 PM  
Jack Mitchell--972-496-6561  
jackmitchell5225@aol.com  
Travis Mitchell--214-820-2608  
travism@BaylorHealth.edu

TEXAS-FORT WORTH  
Moncrief Cancer Resources  
2nd Wednesday, 3:30-5:00 PM  
Valerie Oxford, MSSW  
817-927-6364/838-4863  
Valerie.Oxford@moncrief.com

TEXAS-HOUSTON/TOMBALL  
Tomball Regional Hospital  
2nd. Thursday, 12:00 noon-1:30 PM  
Lynda Tustin, RN--281-401-5900  
ltustin@tomballhospital.org

VIRGINIA-CHARLOTTESVILLE  
Dept. of Forestry Building, Suite 800  
Last Thursday, 12:00 noon-1:00 PM  
Vikki Bravo--434-982-4091  
vsb4n@virginia.edu

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

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  
Kammer@surgery.wisc.edu

## The First Chapter of SPOHNC

In the spring of 1990, I was diagnosed with oral cancer. Several months after my surgery that May, I began looking for answers to questions related to my rehabilitation. I was going through a period of depression and had no one with whom I could share my feelings regarding my physical and emotional problems resulting from my cancer and its treatment. Having some knowledge of how support groups work, I sought out a local support group for head and neck cancer patients. However, such an organization did not exist. I felt strongly that such a support group was essential to helping people cope with this rare disease and its treatments, and I wondered how one could go about starting such a group.

With the support and encouragement of Drs. David P. Wolk, and James J. Sciubba, I began to investigate the possibility of

forming a local organization. After many meetings with Dr. Sciubba, Chairman of Dental Medicine at Long Island Jewish Medical Center, (LIJMC) at the time; the first meeting of Support for People with Oral and Head and Neck Cancer was held. On September 10, 1991, nine survivors gathered at LIJMC to share experiences of coping with a rare disease. This was the first chapter of SPOHNC. Today we have 55 chapters throughout the United States and several more in development.

The primary goal of SPOHNC at that time was to share information, support and encouragement with other cancer survivors. We encompass that goal in our mission today while raising awareness and meeting the needs of oral and head and neck cancer patients. Through a National Survivor Volunteer Network of more than

135 volunteers, a web site at [www.spohnc.org](http://www.spohnc.org), a national newsletter and local chapters, we strive to carry out our mission.

Since that first meeting in 1991, SPOHNC, a not-for-profit, 501 (C) (3) organization, has reached out to thousands of survivors, their families and friends and healthcare professionals involved in the care of oral and head and neck cancer patients throughout the United States and in some foreign countries as well. As our organization continues to grow and more chapters develop, we pay tribute to those who "walked in our shoes."

*Nancy E. Leupold*

Locust Valley, NY  
Survivor, President & Founder  
SPOHNC

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