



**S•P•O•H•N•C**

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

## **ORGAN PRESERVATION SURGERY:**

### **Is Total Removal of the Larynx**

### **Always Needed After Radiation Failure?**

GREGORY S. WEINSTEIN, M.D.

#### **What does it mean to save the larynx?**

The fundamental functions of the voice box are swallowing, breathing and speaking. When working properly, the voice box, a complex valve located above the windpipe, prevents saliva and food from going down the wrong pipe, into the windpipe. If the function of this delicate organ is crippled by treatment, whether surgical organ preservation or radiation with or without chemotherapy, it may not work correctly which can result in the need for a long term gastrostomy tube (a tube inserted directly into the stomach for administration of liquid feedings).

Normal functioning of the voice box also permits breathing through the mouth and nose. A permanent tracheostomy (breathing tube into the windpipe below the voice box ) after organ preservation with surgical approaches or radiation with or without chemotherapy, would be a complication of treatment, and not the typical expected outcome. The voice box is also very important for speaking. It can essentially be thought of as a generator of a tone. Thus, the true test of the value of a treatment for saving the voice box, be it surgical or non-surgical, is at the point when no local recurrence is expected, (about two years or so for most treatments). At this point, is the patient speaking and eating without a permanent tracheostomy or gastrostomy tube?

Most patients, when given the diagnosis of cancer of the larynx, assume that if they have surgery, it will mean loss of the voice box and loss of speech. This is a misunderstanding. Even if the only surgical alternative is total removal of the voice box, patients can be rehabilitated and can speak again. There are several ways in which

speech tone can be generated: 1. with an electrical device that creates a tone (an electrolarynx), 2. with air expelled from the esophagus (esophageal speech) or 3. with a one way valve that is surgically placed between the windpipe and the esophagus to allow air to be pushed from the lungs to the throat, making the throat vibrate and generating the needed "tone" to speak (a voice prosthesis).

Quality of life studies have shown that the major concern after a total removal of the voice box is not the inability to speak, but the need for a permanent breathing hole in the neck, called a stoma. While there is an occasional patient who would rather succumb to the cancer than lose his/her voice box, most patients would agree with the comment of one of my recent patients whose cancer persisted after chemotherapy and radiation therapy and who required a total laryngectomy. "Saving my voice box would be a good thing, but long life is the priority."

Why focus on total laryngectomy in an article about saving the voice box? All treatments that try to save the voice box have some risk of recurrence of cancer in the larynx. Although a patient undergoing radiation therapy for a T1 (T1 is the smallest cancer, T4 is the largest with T2 and T3 being in between) cancer of the vocal cord has a low risk of recurrence, on the order of 10%, there is still some risk. In the majority of studies, a patient with a T2 glottic carcinoma has an approximate 30% risk of local recurrence following radiation therapy. Larger cancers have a higher risk of failure following either radiation therapy alone, or in combination with chemotherapy. Two important points must be considered: 1. In standard practice, full dose radiation can only be given to one body part per lifetime, therefore recurrences following radiation with or without chemotherapy are treated surgically. 2. The vast majority of cancer of the voice box that recurs following radiation with or without chemotherapy requires total removal of the voice box, at least. The latter is true even when the cancer is a small T1 cancer prior to radiotherapy. There is, however, a select group of patients that have recurrence after radiation therapy alone that may not need removal of the voice box. Patients from this group remain candidates for surgical procedures that spare enough of the voice box, that the patient can speak and eat without a permanent tracheostomy or feeding tube. The surgical procedures are collectively known as Organ Preservation Surgery for laryngeal cancer.

#### **Organ Preservation for Laryngeal Cancer**

Our discussion begins with a review of the surgical approaches to save the larynx as an alternative to non-surgical therapies such as radiation therapy alone or radiation therapy with chemotherapy.

The vertical partial laryngectomy was introduced in the 1800s. This was the mainstay of surgical procedures for many years, and its use was mainly for very early cancers of the vocal cord itself. Then in the 1940s a new technique known as the supraglottic partial laryngectomy was introduced for managing early and some intermediate sized cancers of the upper portion of the voice box, or the epiglottis.

PRESERVATION 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  
Email: info@spohnc.org Web site: http://www.spohnc.org

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**  
**Louis Frillmann**  
**Karrie Zampini, CSW**

MEDICAL ADVISORY BOARD

<b>Linda K. Clarke, MS, RN, CORLN</b> Greater Baltimore Medical Center	<b>David G. Pfister, M.D.</b> Memorial Sloan-Kettering Cancer Center
<b>Keith Heller, M.D., F.A.C.S.</b> North Shore-LIJ Health System	<b>Jed Pollack, M.D.</b> North Shore-LIJ Health System
<b>Alex Keller, M.D., F.A.C.S.</b> North Shore-LIJ Health System	<b>James J. Sciubba, D.M.D., Ph.D.</b> Johns Hopkins Medicine
<b>Eugene N. Myers, M.D., F.A.C.S.</b> University of Pittsburgh School of Medicine	<b>Elliot W. Strong, M.D., F.A.C.S.</b> Memorial Sloan-Kettering Cancer Center
<b>David Myssiorek, M.D.</b> North Shore-LIJ Health System	<b>Denise M. Vey Voda, M.A., D.D.S.</b> North Shore-LIJ Health System
<b>Herman Oliver, M.D., F.A.P.A.</b> North Shore-LIJ Health System	<b>David P. Wolk, M.D., F.A.C.S.</b> North Shore-LIJ Health System
<b>Karrie Zampini, CSW</b> Memorial Sloan-Kettering Cancer Center	

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 ©2001–2002  
All rights reserved.

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

A Time for Sharing.....	4
Head and Neck Teleconference.....	5
SPOHNC Turns 10.....	6

COMING IN OCTOBER, 2001

Nasopharyngeal Carcinoma  
Nancy Lee, M.D. and K. Kian Ang, M.D.

PRESERVATION continued from page 1

These two techniques formed the core approaches of conservation surgery of the voice box. While the conservation surgery approach allowed for the saving of many voice boxes for selected early cancers, the procedures didn't work as well for intermediate and advanced cancers. Since these procedures worked best for early cancers, the patients with large cancers underwent total removal of the voice box which was a reasonable approach, because the prevailing logic was that radiation alone for the more advanced laryngeal cancers was not as good as total laryngectomy followed by radiation therapy in terms of cure.

In the 1980s a large study known as the VA trial was done. In this trial, patients with advanced cancer of the voice box were given chemotherapy. Those patients who had at least a part of their tumor shrunk by chemotherapy went on to get radiation therapy. Among the patients in the VA trial who underwent treatment with chemotherapy first, approximately 65% saved their voice boxes and had equal survival to the total laryngectomy group. This was a breakthrough. Then in 1991, a national study known as RTOG 91-11, compared radiation alone, in one group, to a second group receiving chemotherapy first, and a third group receiving chemotherapy and radiation therapy together. The results of this protocol seemed to indicate that the third arm, using chemotherapy and radiation therapy together, was the best for voice box preservation. These two large experimental protocols were reasonable because when they were started, 10 to 20 years ago, surgery only offered techniques to effectively save the voice box for the early cancers, and the ultimate goal was to try and avoid total removal of the voice box in more patients.

Then, in the midst of the clinical trials in the United States with radiation therapy and chemotherapy, a surgical technique from Europe, known as the Supracricoid Partial Laryngectomy, was introduced. The Supracricoid Partial Laryngectomy was first developed in 1959 in Eastern Europe, but was not introduced into the United States until 1989. There are actually two types of Supracricoid Partial Laryngectomies; one for vocal cord or glottic cancer, and one for epiglottic or supraglottic cancer. These techniques allow for approximately 90% chance of saving the voice box for intermediate and advanced voice box cancer, and allow for speech and swallowing without a permanent tracheostomy. The side effects of the Supracricoid Partial Laryngectomy are temporary tracheostomy, temporary feeding tube and permanent hoarseness. Despite these temporary and permanent side effects, a quality of life study has shown that these procedures are superior to total removal of the voice box in terms of social functioning, eating and speaking.

When used appropriately, the Supracricoid Partial Laryngectomy, offering a laryngeal preservation of approximately 90%, is superior to either radiation alone or radiation with chemotherapy for equivalent lesions. Because the Supracricoid Partial Laryngectomy was only introduced into the United States in the 1990s, it has only recently become readily available to patients throughout the country. The introduction of this procedure has created a renaissance in the United States in the use of surgical techniques to preserve the larynx.

On the smaller end of the cancer spectrum, the addition of endoscopic techniques for the removal of cancers through the mouth without cutting through the skin of the neck with or without the use of a laser, have revolutionized the management of early cancers. These minimally invasive surgical techniques have changed the way sur-

PRESERVATION continued on page 3

PRESERVATION continued from page 2  
geons manage laryngeal cancer in the United States. In the past, patients were readily sent to radiation therapy for early cancers, because the alternative was an open approach using vertical partial laryngectomy. This was understandable as the cure rates are equal using either radiation therapy or vertical partial laryngectomy for T1(early) glottic or vocal cord cancer. Surgery also indicated a need for a tracheostomy, and patients experienced more hoarseness following treatment. With the introduction of modern endoscopic approaches in the last two decades, carefully selected patients undergoing outpatient endoscopic surgery without a tracheostomy can have equivalent voices compared to those patients undergoing five to seven weeks of radiation therapy. Endoscopic approaches have also been introduced for early epiglottic or supraglottic cancers. These approaches allow for fewer side effects than open supraglottic laryngectomy and are reasonable alternatives to radiation therapy in selected cases.

The addition of the Supracricoid Partial Laryngectomy and the endoscopic approaches have taken us beyond the traditional conservation laryngeal approach having value for only early cancers, to the organ preservation surgery approach having approximately 90% laryngeal preservation rate for selected T1, T2, T3 or T4 laryngeal carcinomas.

The standard of care in the United States requires that patients who are newly diagnosed with voice box cancer be assessed for both organ preservation surgery and non-surgical organ preservation approaches. The risks, benefits and alternatives of all surgical and non-surgical approaches must be explained to patients, and then they can decide which approach they prefer.

### Summary

Many patients who might have initially been candidates for organ preservation surgery approaches, choose to undergo radiation therapy with or without chemotherapy. Although most patients who fail radiation therapy with or without chemotherapy require total removal of the voice box, there is still a significant number of patients who are candidates for organ preservation surgery approaches using either endoscopic approaches, vertical partial laryngectomy, supraglottic partial laryngectomy or supracricoid partial laryngectomy. While the results of Organ Preservation Surgery are generally better if

the patient has never had prior radiation, results can be excellent even after radiation when performed by a competent organ preservation surgeon. In my opinion, all patients who fail radiation therapy should be evaluated by a surgeon who regularly uses all of the organ preservation surgical techniques to determine if the patient is a candidate for one of them. If, after consultation with the organ preservation surgeon, the patient is told that he/she needs a total laryngectomy, he/she will then realize that a total laryngectomy is the only alternative.

*Editor's Note: Gregory Weinstein, M.D., FACS, Associate Director of the Center for Head and Neck Cancer, at the University of Pennsylvania Medical Center in Philadelphia Pennsylvania, has an international reputation for expertise in organ preservation for cancers involving the larynx. Dr. Weinstein was the first surgeon in the United States to perform the larynx preserving surgery, the Supracricoid Partial Laryngectomy, and has been the primary instructor of this procedure nationally. His textbook, entitled Organ Preservation Surgery for Laryngeal Cancer, published in 2000, has provided an excellent reference for surgeons interested in applying these surgical techniques. ■*

### References

1. Brandenburg JH. Laser cordotomy versus radiotherapy: an objective cost analysis. *Ann Otol Rhinol Laryngol* 2001; 110(4):312-8.
2. Induction chemotherapy plus radiation compared with surgery plus radiation in patients with advanced laryngeal cancer. The Department of Veterans Affairs Laryngeal Cancer Study Group [see comments]. *N Engl J Med* 1991; 324(24):1685-90.
3. Laccourreye O, Weinstein G, Brasnu D, et al. A clinical trial of continuous cisplatin-fluorouracil induction chemotherapy and supracricoid partial laryngectomy for glottic carcinoma classified as T2 [see comments]. *Cancer* 1994; 74(10):2781-90.
4. Myers EN, Wagner RL, Johnson JT. Microlaryngoscopic surgery for T1 glottic lesions: a cost-effective option [see comments]. *Ann Otol Rhinol Laryngol* 1994; 103(1):28-30.
5. Rudert HH. Laser surgery in the management of carcinoma of the supraglottic larynx and hypopharynx. *Adv Otorhinolaryngol* 1998;12.
6. Viani L, Stell PM, Dalby JE. Recurrence after radiotherapy for glottic carcinoma. *Cancer* 1991; 67(3):577-84.
7. Weinstein GS, El-Sawy MM, Ruiz C, et al. Laryngeal preservation with supracricoid partial laryngectomy results in improved quality of life when compared with total laryngectomy. *Laryngoscope* 2001; 111:191-199.
8. Weinstein G, Laccourreye O, Brasnu D, Laccourreye H. *Organ Preservation Surgery for Laryngeal Cancer*. San Diego: Singular Publishing Group, 1999.
9. Weinstein GS, Laccourreye O, Rassekh C. Conservation laryngeal surgery. In Cummings C, Frederickson JM, Harker LA, et al., eds. *Otolaryngology - Head and Neck Surgery*, Vol. 3. Philadelphia, Pennsylvania: W.B. Saunders, 1998. pp. 2220-2228.
10. Weinstein GS, Perlman A, Jones, D.L., Laccourreye O, Alt LP. Functional analysis of speech and deglutition following supracricoid laryngectomy. Annual Meeting of the American Academy of Otolaryngology - Head and Neck Surgery. San Diego, California, 1990.
11. Weinstein GW, Rassekh C, Panniello R, et al. Factors Influencing Local Control Following Supracricoid Partial Laryngectomy. A Multiinstitutional Study. Fifth International Conference on Head and Neck Cancer. San Francisco, California, 2000.



Helping to Build Awareness of  
Oral and Head and Neck Cancer

Support SPOHNC  
and  
help raise awareness by ordering your  
1 inch enamel pin now.

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

To order  
Call  
1-800-377-0928  
or order from our web site beginning  
October 1, 2001

### DID YOU REMEMBER?

Please check the date on the  
address label of your newsletter  
and renew your membership  
before the subscription runs out.

You may complete the application  
found on page 7 of  
News From SPOHNC  
and send it and your check or  
money order to:

SPOHNC  
P.O. Box 53  
Locust Valley, NY 11560-0053

## A TIME FOR SHARING

At the age of 20, my life had been smooth sailing, seldom interrupted with adversity or difficulty. I was a junior at the University of California at Berkeley. I was confident, smart and athletic.

Though I wasn't overly concerned with my appearance, I also knew I was handsome. But during my junior year, over a period of a couple of weeks, several people asked me what was wrong with my nose. I finally took notice of the bump pushing against my right nostril, but it didn't seem like a big deal. I just assumed it would go away. When it didn't, I made an appointment with a doctor who suggested a biopsy.

It turned out that I had a tumor - a rare fibrosarcoma. Although the bulk of it had been removed during the biopsy, my doctor said I'd need follow-up surgery to excise any remaining tumor cells. I wasn't alarmed; my assessment of the situation was that I had little to worry about. The procedure proved to be minor. With only a few sutures alongside of my nose and a few more inside my pallet, I returned to classes looking like I had been in a fight with *someone*, not *something*.

But six months later, I discovered a new lump rising from the lower portion of my right nostril. Then I began to feel tingling in my cheek. Visits to numerous specialists confirmed that my previously unthreatening tumor had procreated itself into a horrific, life-threatening and potentially disfiguring malignancy. My doctor informed me that I could lose half my nose, half my upper lip and possibly my right eye, but that saving my life was his main concern. I suppose I was too young to contemplate dying, but the realization that I could be disfigured was devastating.

I awoke from the first surgery with a skin graft attached to my face from the skin and fat of my shoulder and chest. Half my nose and upper lip was gone, the muscle and bone from my right cheek had been excised and the shelf of my eye, six teeth and part of my hard palate had been removed. My doctor's only promise to me was that he would make me "streetable" before I left the hospital. I did not understand at the time that that was his way of preparing me for a life of disfigurement.

When I was released from the hospital, I noticed adults staring at me and children pointing and sometimes laughing at me. I realized that my hospital room had protected me. Outside of it, I was vulnerable and exposed. How was I going to face the world? I cared what other people thought of me. I relished the admiring looks I had received as the "old Terry" and was petrified of the reaction I'd get to the "new Terry."

Over the next few months, I encountered many old friends and acquaintances. Their sometimes inadvertently negative reactions and comments left an indelible mark on me. On top of what people were saying, radiation treatments had begun to shrink the tissue on my face, magnifying my deformity. My self-esteem sank lower than I thought possible. I found myself constantly seeking reassurance from people - did my looks

*Cancer left him with scars everyone could see. But the worst ones were invisible.*

bother them? What did they see? Did they like me? How could they like me?

Five years later and after 20 attempts to reconstruct my face, I was still coping with the insecurity.

When I went in for my last reconstructive procedure, I met a woman who was also being treated at the hospital. We began dating. One day, after listening to me ask her, for the umpteenth time, how she felt about my looks, she ripped into me. The bulk of my problem, she informed me, was not my physical appearance, but my emotional insecurity. Her honesty helped me to realize that surgery would not fix the mental and emotional scars that had become far more disfiguring elements than the appearance of my face ever had.

I began to examine myself from the inside out. The support of family and friends, prayer and the realization that my scars were deeper on the inside than the outside all combined to strengthen my spirit and belief in

my self. I became a volunteer at the Wellness Community, a cancer support organization that offers hope and support for patients and their families.

Helping others seemed to be the greatest form of therapy. I began to feel better about myself as I realized that I could bring tremendous inspiration and hope to those coping with cancer. Over time, the pain I felt from being an outcast subsided.

Perhaps I will always be an outcast, but it's not pain I feel any more. In a strange way, I am thankful for who I am today - much stronger and wiser than I was before cancer.

We all struggle with insecurities in one form or another. For me it took something devastating - something that would take me to the depths of self evaluation - to realize that battle scars are what make people interesting; battle scars are what make people wise; battle scars are what make people realize how precious and valuable life really is; battle scars are what prepare people for the inevitable adversity that lies ahead. My cancer and disfigurement taught me one of life's most important lessons: It is our internal spirit and not our external appearance that makes up the human soul.

Fifteen years later, I remain free of cancer. I've accomplished a lot personally and professionally. Married to an extraordinary and supportive woman, I am truly content with myself. I don't cower around others or hold my head down any more. In fact, I don't even think to mention what happened to me when I meet people. Perhaps they wonder or perhaps they don't. They sure don't seem as curious as they used to. I guess that tells you something.

Terry Healey  
Alamo, CA

*Editor's Note: Terry Healey is a marketing consultant who lives in the San Francisco Bay Area. He has also written a book about his struggle with cancer and disfigurement called *At Face Value: My Struggle With A Disfiguring Cancer* that was released in July 2001 and is available via his web site at <http://www.at-face-value.com> or through traditional book retailers and e-tailers. You can also contact the author via email at [terry@at-face-value.com](mailto:terry@at-face-value.com).*



## SPOHNC and Cancer Care, Inc. Host Second Head and Neck Cancer Teleconference

“Treatment Options of Radiation For the Head and Neck Cancer Patient,” was the topic of the free teleconference workshop held on June 13, 2001. This workshop was funded by an educational grant from ALZA Pharmaceuticals and co-hosted by Cancer Care, Inc. and SPOHNC. More than 550 people from all over the United States, Canada, the United Kingdom and Australia participated in this teleconference.

Jed Pollack, MD, Attending Physician in the Department of Radiation Oncology at North Shore-Long Island Jewish Health System began the teleconference with a presentation that included a general overview of head and neck cancer and the standard treatment modalities with an emphasis on the types of radiotherapy that are presently in use.

Standard radiation therapy is suitable for patients with small to intermediate size tumors and has the advantage of avoiding surgical risk, possibly preserving organs and hopefully organ function, as well as being able to easily treat large areas of tumors or potential tumor involvement that might otherwise be difficult to reach. However, acute and latent side effects of radiation therapy can be quite severe including malnutrition, dehydration, radiation ulcers, mucositis, dry mouth and swallowing and dental problems.

Hyperfractionated radiation therapy which implies that at least two radiation fractions per day are given for part or all of the treatment, decreases the overall treatment time and appears to make radiation therapy more affective. The rationale for this type of therapy is that it allows less time in between treatments for the tumor cells to recover from the radiation damage.

Hyperfractionated irradiation combined with chemotherapy is also being used to try and increase the effectiveness of radiation in locally advanced head and neck tumors and to decrease the 15-20% rate of tumor metastasis. Combining radiotherapy and chemotherapy may also help to avoid surgery and preserve organs and organ function. There are two ways that chemotherapy and radiation are being combined: sequentially and concurrently (simultaneous chemotherapy and radiation). Although local control rates of 70-85% have been achieved using con-

current chemotherapy and hyperfractionation therapy, toxicity is significant and a feeding tube is almost always required

Radplat is another technique that combines chemotherapy and radiation. In this type of therapy, the chemotherapy agent is delivered directly to the tumor through its own arterial blood supply.

Dr. Pollack continued with a discussion of the technical improvements that have been made in 3D Conformal Radiation Therapy and in Intensity Modulated Radiation Therapy. Both of these treatments use the same type of linear accelerators and x-ray beams as are used in conventional radiotherapy, but in different ways. Treatments are based on CT scans and/or MRI scans for 3-D planning of treatment. Three dimensional imaging of structures such as the spinal cord and salivary glands are also done to help plan treatment and spare these structures from radiation. These types of therapies allow for higher doses of radiation delivery without an increase in side effects and complications,

Stereotactic radiation therapy for head and neck cancer is still in its infancy and in Dr. Pollack's opinion, mostly limited to boost treatments for nasopharyngeal carcinoma and skull base tumors. It is not suitable as stand alone, only treatment for head and neck cancers.

In concluding his presentation, Dr. Pollack addressed the risks that patients face in developing side effects of treatment such as dry mouth, malnutrition and dental problems. In recent years, the use of amifostine has been helpful in reducing radiation induced xerostomia. This is a drug given intravenously and more recently sub-cutaneously just prior to radiation therapy treatments. Another drug, Salagen, has been helpful in stimulating salivary function. Amifostine along with Salagen seem to decrease the probability of permanent xerostomia although they do not eliminate it altogether.

Dr. Kenneth S. Hu, attending Physician in Radiation Oncology at the Charles and Bernice Blitman Department of Radiation Oncology and Beth Israel Medical Center presented information about brachytherapy as an option of radiation therapy in the treatment of head and neck

cancer. Brachytherapy is the actual placement of radiation forces into the tumor bed or cavity itself. Treatment is given directly to the tumor bed without having to go through a lot of normal tissue. Over the past ten to twenty years there has been improvement in the treatment planning software as well as development of better radioisotopes so that the delivery of brachytherapy is more precise and less toxic.

However, brachytherapy can only be used when a tumor bed is implantable. Cancer of the oral cavity (oral tongue and floor of mouth) and the oropharynx (base of tongue and tonsil) and the skin (lip, nasal cavity and chin) have been successfully treated with brachytherapy. Brachytherapy has also been successful as a boost treatment for early stage nasopharyngeal carcinoma together with external beam treatment with or without chemotherapy as well as for recurrent early stage nasopharyngeal cancer. In addition, recurrent cancer in the neck has also been successfully treated with brachytherapy even though the neck may have been previously irradiated with external beam radiation. The primary toxicities associated with brachytherapy include soft tissue complications such as ulcers and wound healing problems, delayed mucositis and osteoradionecrosis.

Dr. George Laramore, Chairman of the Department of Radiation Oncology at the University of Washington School of Medicine in Seattle, WA spoke about heavy particle radiation with an emphasis on fast neutron radiotherapy for treatment of salivary gland tumors.

Dr. Laramore began his presentation with an explanation of the different kinds of particles that are used in radiotherapy for the treatment of head and neck cancer including electrons, neutrons, protons and the heavier particles. Because of the complexity of operations involved in the delivery of heavy particle radiotherapy, only a few facilities in the US offer these types of radiation.

Neutron radiotherapy has been shown to be effective in the treatment of salivary gland tumors. Studies have indicated very good local control of tumors of less than 4 cm. However, since neutrons deposit more energy to the tis-

See TELECONFERENCE on page 7

# SPOHNC TURNS 10

by Janine Cortese

It was a morning filled with deep meaning for all who participated. On Sunday, June 3<sup>rd</sup>, SPOHNC celebrated its 10<sup>th</sup> anniversary and honored oral and head and neck cancer survivors with family, friends and guest speakers. At a buffet breakfast held at the Chateau Briand Restaurant in Long Island, New York, over 200 guests celebrated the occasion with SPOHNC founder and president, Nancy Leupold and special speakers Mr. Alan King, Dr. James Sciubba and Dr. Keith Heller.



Mr. Alan King, Dr. Keith Heller, Dr. David Wolk, Dr. James Sciubba, Dr. John Fantasia  
Mrs. Nancy Leupold

While guests enjoyed breakfast, the program began. Master of Ceremonies, Mr. Carmine Puleo, introduced Mrs. Nancy Leupold. Nancy launched SPOHNC's newly developed awareness ribbon. With a burgundy stripe flanked by bands of ivory, this ribbon symbolizes oral and head and neck cancer. With the distribution of this ribbon, SPOHNC hopes to help raise awareness of this rare form of cancer.

Dr. Sciubba spoke of "Awareness of Oral Cancer and the Importance of Early Detection" and then introduced Mr. Alan King. Alan King is truly a man for all seasons: comedian, actor, producer, author, philanthropist and political activist. Mr. King took the podium and from his first words, effortlessly captivated the audience. He seamlessly moved from paying tribute to Dr. Sciubba and Dr. Heller for his own cancer treatment, to recounting humorous personal anecdotes.

Dr. Heller spoke of the advances in treatment in his presentation entitled, "Head and Neck Cancer 2001." He also announced that Nancy Leupold will receive the Presidential Citation from the American Head and Neck Society at its annual meeting in the Spring of 2002. This honor is an affirmation of all that SPOHNC has achieved in a decade.

Eleven years ago Nancy was diagnosed with oral cancer. She suddenly found herself with many questions and concerns that only someone with the same experience could answer and address. With the encouragement and support of Dr. Jame J. Sciubba and Dr. David

P. Wolk, SPOHNC was born. From a modest beginning of eight people meeting monthly at Long Island Jewish Medical Center to share their experiences, SPOHNC has grown into an incorporated non-profit organization that reaches people throughout the United States and the world. There are currently fifteen local chapters of SPOHNC in the United States with several others in development. With a newsletter, web site and "Survivor to Survivor Network", SPOHNC continues to grow.



SPOHNC-LONG ISLAND members who served on the Celebration Committee

Many people and organizations gave their time and financial support to make the Celebration possible. Volunteers from the Long Island SPOHNC chapter formed committees to oversee all aspects of planning. Survivors were able to attend as guests of SPOHNC thanks to the support of pharmaceutical companies such as Alza, Aventis, Laclede, Matrix and MGI Pharma. Other pharmaceutical companies, local businesses and friends supported SPOHNC's Commemorative Journal which was published and given to each participant. Each guest also received a tote bag filled with gifts from our sponsors.

Bobbi Clyne (a founding member) and Bob Klauber, of SPOHNC-LONG ISLAND, presented Nancy with a plaque of appreciation from all the members. Lynn Gormley recorded the events on video. A slide show prepared by our dedicated web-master, Barry Sebastian, can be viewed on [www.spohnc.org](http://www.spohnc.org).

The morning came to an end with a special tribute to all cancer survivors present, some from as far away as California, Ohio and Florida. Each survivor was asked to stand and be recognized. Holding baskets of flowers, four presenters walked among the tables and honored each survivor with a handful of flowers. As the survivors stood before their family, friends and other guests, the feeling in the room was one of awe for the courage, hope and faith it had taken for these survivors to be able to stand together on this National Cancer Survivors Day. ■



Micki Naimoli, survivor and coordinator of SPOHNC-NJ-PA

**TELECONFERENCE from page 5**

sues, side effects may be greater than those of standard radiation therapy. Intense mucositis and more latent side effects such as fibrosis or toughening of the tissue, have been observed.

Salagen is being used to stimulate saliva and make it easier for the patient to complete neutron radiation treatment. At the present time, amifostine is being investigated to help reduce xerostomia (dry mouth). However, because of the different mechanism of action in neutron therapy, it is not clear that amifostine will have the same degree of protection that it offers in conventional radiation therapy.

At the present time, there are only three centers in the United States where neutron therapy is available for the treatment of salivary gland tumors. One is at the University of Washington in Seattle, a second is in Detroit, MI and the third is in Batavia, IL.

Dr. Laramore continued his discussion with an explanation of proton therapy which is offered at Loma Linda University Medical Center in CA and will be offered at Massachusetts General Hospital in Boston, later this year. He also commented on heavy charge particle radiotherapy being in its infancy and presently available only in Japan and Germany.

Oral complications of radiation therapy was the topic addressed by Dr. James J. Sciubba, DMD, PhD, Director of Dental and Oral Medicine at Johns Hopkins Medical Center, in Baltimore, Maryland.

As radiation therapy is being delivered to a tumor site, there is often damage to the surrounding tissue. Early on in treatment, the patient may experience a redness of the skin of the face, the side of the face, the neck and the jaw area. This is known as radiation dermatitis, which can be likened to intense sunburn, which will diminish over time. Shortly into the treat-

ment, patients will begin complaining of a "dry mouth." This is caused by the effect of the radiation on the major salivary glands (parotid and submandibular) in the field of the radiation beam. Most patients will experience a gradual diminution in salivary flow during treatment. The rate of this flow is variable from patient to patient. However, amifostine, a radioprotective chemical, approved by the FDA, may be able to preserve significant levels of salivary gland function if given just prior to each tumorcidal dose of radiation. In addition, recent studies have shown that the use of pilocarpine before, during and following radiation treatment, provide positive benefits in long term improvement of salivary flow.

Saliva is much more than water on a compositional basis. It is a very complex compound that is extremely important for maintaining and preserving good oral health. Consequently, an individual who has received conventional radiation and experiences moderate to severe dryness (xerostomia) will begin to develop dental cavities or caries unless specific dental preventive and treatment measures are undertaken. These can develop quickly and may run rampant. Patients will also notice a loss or reduction in taste earlier on in the treatment phase. This is a result of the radiation to the taste buds and also to the nerves that transmit the sense of taste to the brain. An alteration or loss of the sense of smell may also occur depending on where the radiation beam is directed.

Dr. Sciubba went on to discuss how radiation affects the small and intermediate blood vessels. Small clots can develop causing congestion and local inflammation, tissue destruction, and increased permeability of those blood vessels. Ultimately there is scarring or thickening around the vascular structures starting about

six months post radiation. The consequence of this is a net loss of the fine blood vessel supply to tissues and bone. This loss of small and medium size blood vessels and attendant fibrosis and scarring may result in a condition known as trismus, difficulty in opening the mouth. To avoid this well known complication of radiation therapy, exercises including stretch therapy and muscle therapy should be practiced during the latter phase of radiation.

Osteoradionecrosis is another potential late complication of radiotherapy. This is a condition, caused by the loss of small and intermediate sized blood vessels within bone and its covering tissue, the periosteum, that leads to a deficiency of oxygen within the bone (hypoxia) and consequently problems in healing of the bone if injured or surgically manipulated. Therefore, dental treatment, including extractions of teeth, should take place 2-3 weeks prior to the onset of radiation therapy. Following completion of radiation therapy it is crucial that routine dental treatment and stringent preventive measures be maintained for the life of the patient.

Dr. Sciubba concluded his presentation with some suggestions for the management of xerostomia (dry mouth) that include the use of stimulating salivary agents such as pilocarpine or Salagen and a newer drug called cevimeline or Evoxac, a drug with similar properties to pilocarpine. To avoid complications of treatment and promote improvement in life style, scrupulous oral care must be practiced including the daily use of topically applied fluorides and frequent, routine visits to the dentist ■

*To hear the complete teleconference, please visit our web site at [www.spoync.org](http://www.spoync.org)*

---

**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**

- \$20.00 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+

HEAD AND NECK CANCER SUPPORT GROUPS IN THE UNITED STATES

PHONE #  
404-284-8045  
561-395-7100  
617-731-1703  
732-356-1939  
703-698-2813  
281-259-4110  
516-759-5333  
631-543-3154  
212-288-5718  
305-596-6566  
305-243-4952  
856-722-5574  
402-559-7561  
412-647-9127  
760-751-2109  
973-971-5169  
414-454-5631  
202-784-3755  
503-413-7834  
410-828-2087  
614-293-6428  
718-780-1801  
212-717-3527  
215-707-4924  
734-936-6037

COORDINATOR/FACILITATOR  
Harmon Grotzky  
Darci Lipson-McNally, LCSW  
Valerie Goldstein  
Bernadette Maszczak  
Pam Black  
William A. Phelan  
Nancy Leupold  
Alice Peters  
Barney Phair  
Marsha Braunstein, RN  
Penny Fisher, RN  
Micki Naimoli  
Katherine Jones  
Marilyn Hudak, RN  
Valerie D. Targia  
Catherine Owens, MSW, LCSW  
Kathy Myers, RN  
Joanne Assarsson  
Carol Ross  
Linda Clarke/Lynne Delancey  
Kimberly Ann Holle  
Loralee Fulton, RN  
Karrie Zampini  
Stefanie Washburn  
Tammi Miller, RN

SPONSOR  
SPOHNC-ATLANTA, GA  
SPOHNC-BOCA RATON, FL  
SPOHNC-BOSTON, MA  
SPOHNC-BRIDGewater, NJ  
SPOHNC-FAIRFAX, VA-Heads Up  
SPOHNC-HOUSTON, TX  
SPOHNC-LONG ISLAND, NY  
SPOHNC-LONG ISLAND, NY-EAST (now forming)  
SPOHNC-MANHATTAN, NY (now forming)  
SPOHNC-MIAMMI, FL  
SPOHNC-MIAMMI, FL-Mort Silverblatt Head and Neck  
SPOHNC-NJ-PA  
SPOHNC-OMAHA, NE  
SPOHNC-PITTSBURGH, PA  
SPOHNC-SAN DIEGO, CA  
Carol Simon Cancer Center (Morristown, NJ)  
Fredriert Cancer Center (Milwaukee, WI)  
Georgetown University Medical Center (Washington D.C.)  
Good Samaritan Hospital (Portland, OR)  
Greater Baltimore Medical Center (Baltimore, MD)  
James Cancer Hospital (Columbus, OH)  
L.I. College Hospital (Brooklyn, NY)  
Memorial Sloan-Kettering Cancer Center (New York, NY)  
Temple Cancer Center (Philadelphia, PA)  
University of Chicago Hospital (Chicago, IL)



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

“Options of Radiation Therapy  
for the  
Head and Neck Cancer Patient”  
(a teleconference)  
Now available for listening at  
[www.spohnc.org](http://www.spohnc.org)  
\*\*\*\*\*  
Coming in November  
“Recurrent Head and Neck Cancer”  
(a free teleconference)  
November 2, 2001  
\*\*\*\*\*  
The Keith Webb 10K Run  
November 18, 2001  
\*\*\*\*\*  
Details available soon  
Check our web site