RECENT CLINICAL TRIALS IN HEAD AND NECK CANCER

Jed M. Pollack, MD

The management of early stage (Stage I-II) Head and Neck Cancer has been relatively straightforward for many years, involving single modality surgery or radiation, depending on the primary tumor site. While there have been dramatic advances in radiation technology, such as 3-D conformal radiation in the early 1990’s, and IMRT (Intensity Modulated Radiation Therapy) in the last 10 years, and stereotactic radiosurgery in specialized situations, the most important and dramatic advances have been in the treatment of intermediate and locoregionally advanced Head and Neck Cancer (T3-4 primary and/or multiple or large neck nodes, N2-N3), defined as Stage III-IVa.

The major emphasis has been on ways to increase not only cure rates, but also preservation of organ (tongue, larynx, hypopharynx, salivary glands, jaw) and organ function (swallowing, speaking, chewing, salivary flow), by replacing surgery chemotherpay. With the exception of salivary function preservation, which has greatly improved with the advent of IMRT, preservation of organ and organ function has largely been improved upon with combined modality treatment using chemotherapy and radiation, in various combinations, with surgery generally reserved for patients who have had incomplete response to non-surgical treatment. The following is a brief survey of some of the important clinical trials in the last 15-20 years that have led the way forward in the treatment of Head and Neck Cancer.

One of the most obvious sites for attempts at organ preservation has been in patients with intermediate to locally advanced larynx cancer. The Veterans Administration Larynx Trial (VA Larynx Trial) randomized 332 patients with glottic or supraglottic cancer to laryngectomy followed by radiation, or induction chemotherapy (2-3 cycles of 5FU and cisplatin) followed by definitive radiation if there was a good response to chemotherapy. 31% of patients in the chemotherapy arm had a complete clinical response after 2 cycles of chemo, 49% after 3 cycles. 64% of patients in the chemotherapy arm were ultimately able to preserve their larynx, with survival equivalent to those who had upfront laryngectomy. The Intergroup 91-11 trial randomized patients to induction chemo followed by radiation, simultaneous (concomitant) chemo-radiation, or definitive radiation alone. The outcome showed superior larynx preservation with concomitant chemo-radiation, intermediate results with sequential chemo followed by radiation, the poorest results with radiation alone. Overall survival was the same in all three arms.

The GORTEC 2000-01 trial in Europe randomized patients with hypopharynx or larynx cancer to induction chemotherapy with TPF (Taxol/Platinum/5-FU) or PF; then, depending on whether or not there was a sufficient response, to either laryngectomy followed by radiation (RT) or RT alone. Larynx preservation at 3 years was 74% with TPF, 51% with PF. These three studies helped greatly to establish and define the role of cisplatin-based chemotherapy in the treatment of intermediate-locally advanced larynx cancer, and led to similar trials in other Head and Neck Cancer sites, notably in the U.S. and Europe, but in other countries as well. A major unanswered question remains, regarding the need for induction chemotherapy vs. concomitant chemo-radiation only, or both. One of the consistent problems in trials involving induction chemotherapy is the difficulty of getting patients through the definitive radiation afterwards, especially if concomitant chemotherpay is also planned.

The TAX 323 trial involved 358 patients with locoregionally advanced larynx, oral cavity, oropharynx or hypopharynx cancer, randomized to induction TPF or PF, followed by RT alone (TAX 323) or RT with concomitant carboplatin (TAX 324, 501 patients). Both studies showed superior results with Taxol, which has now become a standard part of most induction regimens in Head and Neck Cancer. Overall 5-year survival was 43% in TAX 323 with Taxol vs. 32% with PF only. Overall 5-year survival in TAX 324 was 67% with Taxol, 55% with induction PF only. Of importance was the improvement in survival with the addition of concomitant carboplatin with RT: Overall survival in TAX 324 was 71 months vs. 30 months in TAX 323.

The French GORTEC 94-01 trial randomized 226 patients with locoregionally advanced oropharynx cancer to RT alone or RT and concomitant 5-FU/cisplatin. Final results published in 2004 showed locoregional control of 48% with chemotherapy vs. only 25% with radiation alone. Disease-specific 5-year survival was 25% with chemotherapy vs. 15% with radiation alone. This trial has been questioned for overall unusually mediocre results in both arms of the study. The Intergroup 0099 trial in the U.S. randomized 193 patients with locoregionally advanced nasopharynx cancer to RT alone or RT and concomitant cisplatin. The 3-year progression-free survival rate was 69% with chemo-radiation vs. 24% with radiation only; 3 year survival was 76% vs. 46%.
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The MACH-NC (Meta-analysis of Chemotherapy in Head and Neck Cancer) study reviewed 93 randomized trials involving 17,436 patients. The most recent update was published in July 2009. The absolute survival improvement with chemotherapy overall was 4.5%, but this rose to 8% with concomitant chemotherapy. Of note, the benefit decreased in patients older than 70, and there was no definite benefit found to adding additional drugs to cisplatin, which remains the standard. Based on the above studies, concomitant cisplatin and radiation has become the common “standard of care” for loco-regionally advanced Head and Neck Cancer in the U.S., while the role of induction chemotherapy remains controversial. The University of Chicago, notably, has pioneered multiple trials using various induction regimens, some with Carboplatin and Taxol followed Taxol, Hydroxyurea and 5-FU, with concomitant twice-daily radiation (hyperfractionation). These trials, conducted from 1995-2002, achieved 4 year locoregional control of 85%, with 80% of patients free from distant metastasis. Disease-free survival at 4 years was 54%. The greatest benefit of these intense regimens was found in patients advanced neck disease (N2b-N3), mostly impacting rate of distant metastasis. A summary of five U.S. and European Clinical Trials published in Seminars in Radiation Oncology, January 2009, showed rates of distant metastasis with RT only of 20-40%, decreased to 20% or less with the addition of chemotherapy.

The RTOG 0129 trial focused on the question of hyperfractionation and concomitant cisplatin vs. standard once daily radiation and cisplatin. The interim results do not show a benefit to hyperfractionation. Increasingly, an additional focus has been the use of targeted, biologic therapy, ie. targeting certain growth receptors on the surface of cancer cells, which may provide additive impact on cancer control without corresponding increasing toxicity. A randomized trial, published in Lancet Oncology in April 2010, analyzed 424 patients randomized to radiation alone or with Cetuximab, an anti EGFR (Epidermal Growth Factor Receptor) antibody. 5 year overall survival with Cetuximab was 45.6% vs. 36.4% with RT only. Median survival was 49 months vs. 29 months.

The RTOG 0522 trial randomizes patients with loco-regionally advanced Head and Neck Cancer to accelerated RT and concomitant cisplatin, with or without Cetuximab. Results of this trial are eagerly awaited. Two other important nonsurgical trials are the DeCIDE trial, from the University of Chicago, randomizing patients with advanced neck disease (N2-N3) to induction chemotherapy with TPF followed by RT and concomitant Taxol/5-FU/Hydroxyurea, or chemo/RT alone, without induction chemotherapy, and the PARADIGM trial, multi-institutional study that randomized 145 patients with stage III-IV disease to TPF induction followed by RT and concomitant cisplatin, or RT/cisplatin without induction. Preliminary toxicity results presented this year at ASCO showed no unusual toxicity in either arm. Survival outcomes results are pending.

An additional question has been the role of postoperative chemotherapy added to radiation, in patients with high-risk pathology, such as positive margins, multiple lymph nodes involved in the neck, extra-capsular extension of cancer in the lymph nodes (ECE), perineural invasion or lympho-vascular invasion in the primary tumor specimen. The RTOG 9501 Trial and the EORTC 22931 Trial randomized patients to postoperative radiation alone or with concomitant cisplatin. A combined analysis of both trials, published in Head and Neck, October 2005, showed rates of distant metastasis with RT only of 20-40%, decreased to 20% or less with the addition of chemotherapy.
CLINICAL TRIALS continued from page 2 showed that the major benefit to the addition of chemotherapy was in patients with positive margins or ECE. Overall survival benefit was 28%, and locoregional failure was decreased by 25%. RTOG 0024 is a followup study testing the addition of Taxol postoperatively, both before and during postoperative cisplatin/RT. No results are yet available. RTOG 0920 is an additional postoperative trial randomizing Stage III-IV patients to RT only or RT plus Cetuximab. RTOG -2034 is a trial evaluating postoperative RT and Cetuximab combined with either cisplatin or Taxol.

In summary, the major results of the Clinical Trials in Head and Neck Cancer over the last 15 years have defined the central role of chemotherapy combined with radiation both for definitive nonsurgical treatment of patients with stage III-IVa cancer (locoregionally advanced, but without distant metastases), as well as in the postoperative setting. This multimodality treatment has come at the price of additional acute and some additional long-term toxicity, but has yielded solid improvements both in organ preservation and cure.

Some of the major unresolved questions are:
1. What is the role of induction chemotherapy (chemotherapy before) any definitive chemoradiation? Is it better than chemoradiation without induction?
2. What is the role of Cetuximab in addition to chemoradiation for nonsurgical patients. Should it be combined with RT alone, or used with chemotherapy/RT as well?
3. In the postoperative setting, what is the role of Cetuximab in addition to radiation? Should it be used with or instead of chemotherapy?
4. Is cisplatin alone, combined with radiation, still the standard of care? Is Taxol as good or better? What about multiple chemotherapy agents combined with concomitant radiation?

As the results of the current trials mature, the hope is that we can continue to make additional improvements not only in cure rates and organ preservation and functionality, but also that new standards of care can be agreed upon, that can result in decreased acute toxicity during treatment, and improved long term quality of life.

Editor’s Note: Dr. Jed M. Pollack graduated from the University of New Mexico School of Medicine in 1981. He completed his residency in Radiation Oncology at Memorial Sloan-Kettering Cancer Center in 1985. Dr. Pollack was a full time attending physician in the Radiation Oncology Department at Long Island Jewish Medical Center from 1985 through 2005, with a clinical appointment as Asst. Prof. at Albert Einstein College of Medicine. In 2005, he joined Long Island Radiation Therapy, a division of Nassau Radiology (NRAD).

FROM THE EXECUTIVE DIRECTOR

In August of 2009, I was appointed by the Board of Directors to be the Executive Director of SPOHNC. I feel very blessed to work with so many wonderful and caring individuals, to represent such a remarkable organization, and to help those in need of our support.

Reflecting back over 2010, I am reminded of a quote we used to exemplify our Founder & President, Nancy Leupold, and her legacy here at SPOHNC, “No one is more cherished in this world than someone who lightens the burden of another.” During this past year, as Executive Director, I have had the privilege of working with individuals who have this same sentiment in their daily lives. Our Outreach Program consists of over 300 volunteers who give their time, expertise and support to patients and families who are affected by oral and head and neck cancer. In addition, we have 105 chapters of SPOHNC throughout the United States with several more in development. The commitment of these individuals and the facilitators of our chapters support our organization’s mission to help raise awareness and support oral, head and neck cancer patients and their families in their cancer journeys.

As we approach our twentieth year, SPOHNC has developed a wide range of exceptional programs and essential services for this patient population and their families. Whether it is attending a chapter meeting, being matched with a survivor, reading one of our three publications, navigating on our website for additional information or connecting to our site on Facebook, it is our goal for each and every patient to have access to our many resources. Every day, patients contact us asking for advice, support and encouragement and it is through these resources that they are able to find security in knowing there are others who have “walked in their shoes” and can help them in their healing process. It is our hope to give these patients the empowerment to continue to live a full and productive life during and after their treatment.

A major component of our mission is to raise awareness of oral and head and neck cancer. We had a very exciting year as many of our chapters offered taste events, walkathons, an in-line skating event, and panel discussions during awareness week in April. We encourage oral cancer screenings at these events to inform the public about early detection and to seek medical attention when necessary.

If you are not already a member, I invite you to join SPOHNC. It is our goal to keep you informed of the most current treatments available and to share the poignant stories directly from head and neck cancer survivors. I am looking forward to putting into action additional programs here at SPOHNC. Our ideals are to broaden our audience and to create additional options available.

As we reflect on 2010 and make plans for 2011 remember “No one is more cherished in this world than someone who lightens the burden of another.”

Wishing you all peace, health and harmony this holiday season and throughout the New Year!

Dr. Pollack has been named to New York Magazine’s Best Doctors List for 10 years in a row, and has been on the Castle Connolly list of America’s Top Doctors for the last 14 years.

Dr. Pollack has had a particular interest in the treatment of Head and Neck Cancer for more than 25 years, and continues to work closely with his colleagues in head and neck surgery and medical oncology to provide state-of-the-art care.
A TIME FOR SHARING... A Survivor’s Courage and Determination

Sometime early in 2009, as a 12 year throat cancer survivor and member of SPOHNC’s National Survivor Volunteer Network, I had several telephone conversations with a 4 or 5 year survivor who suddenly developed Osteoradionecrosis, (bone death) of the jaw. This condition is usually referred to as ORN. Then, in one of life’s ironies, a few months later I also developed ORN in my left jaw.

I was no stranger to ORN having experienced a case in my right jaw in 1997 while being treated for a Stage IV tumor in the area of my left tonsil. Despite 40 hyperbaric oxygen treatments and several debridements, the disease progressed until the jaw fractured sometime in 1999. At that time, about a 1 inch piece of diseased bone was removed and a titanium plate installed to bridge the gap and bring strength and stability to the jawbone. But, eventually, the plate had to be removed because of chronic infections. Despite the jaw being fastened on only one side, with rehab and hard work, I was able to restore enough chewing function to the extent that I could eat and chew even the occasional steak or chop although I favored softer foods.

And so it went for about ten years, cancer free and with acceptable function, until an abscessed tooth had to be extracted in the summer of 1999. ORN now developed on the lower left side progressing to a fracture sometime early in December 2009. This was a catastrophe. With a gap on the right and a break on the left, the jaw slipped away from its normal position and it was impossible to chew. After 11 years, I was back on liquid and pureed foods.

I had the abscessed tooth removed in Baltimore at the same medical center that had resected my jaw in 1997, but I did not feel that they had the experience to do the major reconstruction that would now be required. My cancer treatment in 1997-1998, consisting of eight weeks of radiation, chemotherapy, and bilateral neck dissections, had been at the National Institutes of Health (NIH) in Bethesda, MD and during my annual follow-up in December 2009, I sought their advice. I was told that there were few hospitals or surgeons with extensive experience in this difficult and complicated surgery that would be required, but that a visit to a major center in the mid-West might be worthwhile although I should probably not consider having the surgery done so far from home.

In January 2010, I flew from my home near Washington, DC to the mid-West center. The surgeon had reviewed my records before the consultation and my appearance must have surprised him because he said that I was the best patient he had ever seen in terms of function given my history. Even though he too had been initially skeptical about doing the surgery so far from home, he was ready to proceed. I was impressed with what I had seen and heard and felt that my wife and I could work out the distance challenges.

When the jaw fractured, I knew that free flap surgery, involving transfer of bone, soft tissue, and blood vessels from another part of the body to the jaw and neck, would be required. I learned that there were several possible donor sites for the flap and that damage to blood vessels in the neck caused by the radiation and neck dissections would limit the possible blood vessels to be used to attach to the flap. Consequently, the plan was to use a piece of the scapular bone (shoulder blade) and attached muscles and blood vessels that would then be attached to arteries and veins in the upper chest.

In late March 2010, I returned and checked in for what I thought would be an all-day surgery. Four hours later, I woke up in the recovery room and found that, after opening my chest by splitting three ribs from the sternum, the surgeons found that the sub-mammary veins intended to receive the vein from the flap were too small. Three weeks later, I was back for a second attempt. The plan this time was to cut the clavicle (collar bone) and use the sub-clavian blood vessels, but right at the beginning, intubation failed, the airway was blocked, blood oxygenation plummeted, and the surgeon felt that it was too risky to continue even after the airway was cleared.

Another eight hour drive back to Virginia. My wife and I were angry and discouraged and all I had to show for two sixteen hour round trip drives, two pre-surgery airplane round trips, two attempts at reconstructive surgery, and several thousand dollars in non-insurance covered expenses for air fares, rental cars, and hotel stays, plus co-pays, was a very sore chest with a six inch scar from the first attempt. It was time to reconsider.

My primary care physician suggested another opinion and referred me to the chief of head and neck surgery at a major university medical center in Virginia. I also decided to get an opinion from an ENT in DC, also a chief of head and neck surgery, who I had been seeing for follow-ups since my cancer treatment back in 1997. Although I knew that he did not do reconstructive surgery, he said that he often worked with a plastic surgeon in DC who did. They would work as a team with the ENT doing the diseased bone removal and the plastic surgeon doing the reconstruction.

So, now I had been to four major medical centers: (1) the Baltimore-based group which I ruled out due to insufficient experience; (2) the mid-West university medical center and surgeon with a great reputation and significant reconstruction experience who planned on doing a scapular free flap with connections to sub-clavian arteries and veins but had already made two unsuccessful attempts; (3) the Virginia surgeon who recommended that I do nothing with a rationale that, since I did not have much pain and could eat liquid and pureed foods, why undergo the risks and pain of a long and difficult surgery with the possibility of a worse outcome; (4) the DC team which planned to use the radial bone of the forearm, a facial artery, and the cephalic vein in the arm but which I also felt had insufficient experience.

This was a difficult decision. The fact that three highly respected groups at the top of their profession had three very different opinions demonstrated that, although based on some very impressive science, there is still a lot of art in medicine. By now, I was spending a lot of time on the Internet trying to get more information on which to base a decision but eventually the Virginia surgeon suggested that if I really wanted to have reconstructive surgery, then I should visit a surgeon in New York who was one of the best in the country.

Over the next few weeks, I had two visits with Dr. Mark Urken, Chief of Head and Neck Surgery at Beth Israel Medical Center in New York City and his colleague, Dr Daniel Buchbinder, Chief of the Division of Oral and Maxillofacial Surgery. Their plan would be to use the fibula (the smaller of the two lower leg bones) and associated muscle, skin, and blood vessels as the donor site, and the major artery in the neck supplying the jaws and brain (the internal carotid artery) for the arterial supply to the graft, and the cephalic vein to receive the discharge from the flap. However, the surgeon cautioned that the final decision on the donor site would not be made until he knew how much of the jawbone would have to be removed at the beginning of the surgery. Like the mid-West surgeon (with whom he discussed my case – I made sure that everyone knew the opinions of the others), he told me that the complication...
rate for such a complex procedure would be about 100% but that their success rate was close to 100%.

The procedure was done on July 27 and, as predicted, there were complications. The first surgery - with a fibula flap – went well but the next day a thrombosis (clot) developed in the draining vein which required a return to the OR to remove that section of the vein and reconnect the two segments. The next week, the microvascular surgeon examined the flap noting a separation between the flap and the adjacent original or native tissue where vital structures were exposed. This in turn required yet another trip to the operating room where a muscle from the chest was used to fill the gap. Then, a few days later, an infection developed at the tracheotomy site which meant a brief return to the OR to improve the wound drainage and correct some other problems. All told, I spent 23 hours in the OR and under general anesthesia and a total of three weeks in the hospital instead of the anticipated one to one and one-half weeks.

At this writing, it has been almost three months since discharge. When I arrived home, I could barely walk 100 ft; a few weeks ago, my wife and I walked a little more than two miles in a Walk to Fight Breast Cancer. My teeth were bound together with bands during the hospital stay and for several weeks after discharge so as to keep the jaw properly aligned. When the bands were removed, it was almost impossible to bring the teeth together with enough accuracy and force to chew but I kept working at it. A major milestone was about one and one-half months after discharge when I was able to eat part of a hamburger – the first hamburger in almost a year. Last week, I was even able to eat a small piece of steak. I find it almost miraculous that I can chew again after almost a year of teeth not even coming together. It is still not easy and it takes a long time to eat anything that requires chewing. But, as long as I keep working at it, I am confident that continued progress will be made.

What have I learned from this that may benefit others? First, was it worth it? Absolutely! To have such a restoration of function makes all the time, anxiety, attempts to reconcile differing opinions, and prolonged recovery worthwhile.

Next, second or even multiple opinions are critically important. I consulted with people at the top of their professions with impressive skills, learning, and credentials but still ended up with a final decision, which was different from my initial decision. Perhaps most importantly never forget the role of family and friends. My wife, Sue, was there every day for three weeks and my adult daughter, Sarah, for two of the three weeks. I know that not everyone is so fortunate but we can all reach out to church, neighbors, or other groups, such as SPOHNC.

Finally, a small amount of determination will go a long way. I found that, no matter how painful or difficult, it’s important to keep working at rehabilitation. Progress might be slow, even miniscule, and there will be bad days, but attempting to do more each day than the day before, no matter how little, will pay off, eventually.

George Tyson
Alexandria, VA

Editor’s Note: This complex recounting of this one survivor’s experiences emphasizes the complexity of head and neck cancer management and the possible complications resulting from the cancer treatment itself as well as treating those complications. This recounting also demonstrates the single-minded strength and dedication of this survivor and what is possible in spite of the sometimes long odds against success.

FOCUS ON SPOHNC-ILLINOIS EVANSTON/HIGHLAND PARK

At the cancer center where I work, we strive to give our patients excellent and comprehensive care. This includes using a health model in which the psychological and social aspects of patients’ needs are addressed in addition to the medical needs of receiving physical treatment for cancer.

Psychologists, social workers, nutritionists, patient financial advocates all work together to provide comprehensive support to patients. For example, we have a variety of resources including educational literature as well as opportunities for short term outpatient therapy for individuals and families affected by cancer. Additionally, if needed, we provide information regarding how to access financial assistance, transportation assistance, legal services, nutritionist services, wigs, and home health care services.

Part of our role as the psychosocial team is to provide support for patients dealing with normal emotional impact of living with cancer. According to NCCN (National Comprehensive Cancer Network) Distress Management Guidelines, 20-40 percent of newly diagnosed and recurrent cancer patients experience a significant level of distress and may exhibit significant anxiety and depression. At our center, patients may receive free psychosocial assessments during which we discuss adjustment to cancer related issues and provide recommendations to address any cancer related concerns.

We strive to meet with every patient at his/her first treatment appointment for this psychosocial assessment. If patients are interested in receiving further services from the psychosocial staff, we provide supportive therapy (either individually, or with family members) to address adjustment to diagnosis, coping with side effects of treatment, and changes in roles that impact not only the person diagnosed but his or her social community as well. Our goal is to assist in maximizing quality of life for patients and their families while they cope with the challenges of cancer.

An additional role of the psychosocial team is to facilitate support groups. The SPOHNC group at our Cancer Center which serves to support individuals diagnosed with oral, head and neck cancer and their caregivers, was created in order to ensure that patients and families have an opportunity to meet others coping with similar challenges. Our hope is that this group may decrease isolation that sometimes occurs when people are coping with cancer, may decrease stigma sometimes associated with side effects, may normalize common cancer related concerns, may provide the opportunity for emotional processing, and may increase effective ways of coping learned from others in the group.

In addition, we strive to facilitate opportunities to learn from oncology professionals, who provide didactic presentations on topics relevant to head and neck cancer, such as radiation and treatment side effects, genetic probability of recurrence, and the nutritional adjustments that are necessary with this diagnosis during the first hour of the group. The second hour of the two-hour monthly group is devoted to discussing the presentation and any additional topics of interest to group members.

In summary, the psychosocial oncology team seeks to provide individualized, family, and group support to individuals affected by head and neck cancer across the course of their cancer experience.

Stephanie Horgan, LSW, Facilitator
Micki Naimoli is a petite woman with a big heart for helping others. She is also a 13 year survivor of base of tongue cancer, stage 4, who continues to help cancer survivors whenever needed. Ben, her husband of 43 years has always been at her side to help her through her illnesses and also to support her dedication to cancer survivors.

In August of 1997, Micki was diagnosed with Type 1 diabetes. By mid-October it was obvious that she needed to see an endocrinologist for a second opinion. Ben drove her to her appointment at the University of Penn Hospital. It was during this ride that Micki told Ben that she had felt two lumps on the left side of her neck, approximately the size of two walnuts, below her earlobe. Needless to say, she was quite upset.

During her visit with the endocrinologist, Micki told the doctor about the lumps in her neck. He examined them and subsequently, arranged for her to see a head and neck surgeon. The following week, Micki and Ben met with Dr. Randall Weber. In the meantime, the endocrinologist had made arrangements for Micki to have an MRI of her head and neck. The results of the MRI were not good. There appeared to be malignant tumors in her neck.

The endocrinologist recommended that Micki see an ear, nose and throat doctor or a surgeon. She felt a surgeon would be the better choice. As they already had an appointment with Dr. Weber, they decided to keep the appointment with him and consequently, selected him to be the surgeon.

Following an office examination, the surgeon arranged for a needle biopsy to confirm what he felt was a squamous cell carcinoma; the lab report confirmed his diagnosis. Furthermore, he arranged for her to come back to the hospital to meet with a multidisciplinary team of hospital personnel.

Needless to say, she was extremely upset and distraught over the news.

The following morning, Dr. Weber called and spoke to Ben and confirmed their worst fear; the lumps in Micki’s neck were cancerous; he would see her in the hospital early the following week. Later that morning the phone rang. The caller was a cancer survivor whose diagnosis had been similar to Micki’s. She, also, had been treated at the University of Penn Hospital and was doing very well. She wanted to meet with Micki and Ben.

Joann Struck met with Micki and Ben later that morning. She spent several hours explaining the type of treatment she had. It was Joann’s visit that gave Micki and Ben the courage, hope and optimism to help them face the terrible ordeal that lay ahead. Furthermore, her visit and support would eventually be the inspiration for Micki and Ben to create a support group for head and neck cancer patients. She was their light at the end of a dark tunnel.

On Halloween morning 1997, Micki had her surgery. The surgery lasted a number of hours. After the surgery, the surgeon met with Ben and told him he felt everything went well and he would stop up to see Micki later that day before he went home. He did just that, and left Micki with the comment that he was leaving to take his kids “Trick or Treating.”

Micki’s hospital stay lasted four days and at the time of her discharge she met with Dr. David Rosenthal, who would soon be her radiation oncologist. She was to begin radiation treatment two weeks later.

At the time of Micki’s surgery, the surgeon arranged to have a feeding tube put in place, because he knew once into 35 radiation treatments Micki’s ability to eat would be compromised and she would need the feeding tube to maintain good nourishment. She would use this feeding tube for more than ten months.

Before radiation treatments began with Dr. David Rosenthal, Micki had been fitted for a mask so that her position on the table during radiation would be consistent. The doctor reassured her there would be many people to help her in case any problems arose while she was alone on the radiation table with her head secured to the table.

During the radiation treatments, Micki lived at home. Every morning a different neighbor would drive her to the hospital. There were many days when it was difficult to prepare herself to leave for the radiation treatment considering that she had to take an injection of insulin along with feeding herself through the feeding tube. However, knowing that a neighbor was committed to driving her to the hospital, she felt obligated to continue. The entire neighborhood reached out to Micki which provided her with much inspiration and motivation. It got her through a very difficult time. One thing she would do when going through her radiation treatments was to wear bright colored clothing each day; this always lifted her spirits.

Micki also had the support of Dr. Phil LoPresti, a head and neck cancer survivor himself, who called her almost every night during radiation therapy to give her encouragement and hope. He later became one of the original start-up support members, and he continues to participate in the group every month.

During the radiation period, it was difficult to sleep lying down because of the mucositis from the radiation therapy. As a result, most nights Micki would sleep sitting up on the sofa; often watched the cooking channel in the middle of the night. It was almost ten months after the radiation treatments began that she was able to taste anything.

Micki is indeed grateful to the doctors who gave her such good care and showed compassion for her during and after surgery and radiation. They made her survival possible.

She is not certain when she learned about SPOHNC and it’s founder, Nancy Leupold, but she called her very early during her treatments. Nancy’s guidance and advice during this difficult time were extremely helpful. Micki realized how important a support group would be to survivors like herself and consequently during the early days of her follow-up visits with her doctors, she repeatedly asked about establishing a support group for head and neck cancer patients. Unfortunately, Micki was consistently told that establishing a support group was not possible.

Finally, after three years of constantly badgering the doctors about forming a support group and coincidentally, the arrival of a substantial donation by the Abramson family to the University of Penn Hospital, a perfect storm was created. The cancer center provided
Micki and Ben with a nurse and a social worker to assist them in starting a head and neck cancer support group.

On October 6, 2000, Micki, Ben and three other survivors formed the first head and neck support group. The meeting was held at the Abramson Cancer Center in Philadelphia, Pennsylvania.

On April 13, 2008 the University of Penn Hospital had a head and neck cancer conference at a hotel in Philadelphia. Over 700 people, including doctors, nurses, patients and survivors, attended the conference. Both Ben and Micki were honored with the first “Patient Advocacy Award” at the conference.

This past October 6th, Micki’s support group celebrated its 10th anniversary with more than 50 people, most of whom were long time survivors. A number of oncology physicians and hospital staff also attended. The 10th anniversary meeting had a party like atmosphere, many survivors talking about their experiences regarding their treatment and their survival. The support group coordinators, Tracy Lautenbach and Mia Benson Smith, MS, from the hospital provided two decorated cakes. There was not a formal program; it was truly a “Celebration of Life.”

One of the administrators at the hospital informed the group that their head and neck cancer support group was by far the largest and longest running and successful groups in the hospital and possibly throughout the United States. Both Micki and Ben and all the people of the University of Penn Hospital who have been part of the support group, extend their heartfelt thanks to Nancy Leupold and SPOHNC for all the help and inspiration given to the support group over the many years.

Dr. Joe Carver, Chief of Staff of the Abramson Cancer Center, said as he was leaving the 10th anniversary meeting “See you all on the 20th anniversary.”
HOLIDAY GREETINGS TO SPOHNC’S VOLUNTEERS AND CHAPTER FACILITATORS

The upcoming holiday season is a special time to recognize and celebrate all those who have contributed and volunteered their time and expertise to so many.

SPOHNC is very grateful to our volunteers who lend encouragement, hope and support to newly diagnosed patients and those survivors on their cancer journeys. Our National Survivor Volunteer Network and Chapter Facilitators make a big difference to so many lives.

SPOHNC’s growth has reached beyond our expectations, and together we have created a support system so vital to head and neck cancer patients and their families.

Many of you have been SPOHNC volunteers for several years and others have recently joined our organization. We are extremely thankful to you for giving willingly of your time to patients and their families. You are the “true heroes” who day after day carry out SPOHNC’s mission and we are blessed to have so many wonderful and dedicated volunteers.


With sincere appreciation,

MaryAnn Capote

SPOHNC’S RESOURCES

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

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

Meeting the Challenges of Oral and Head and Neck Cancer: A Survivor’s Guide
$24.99
www.spohnc.org
10% Discount code: AP302
Also available at: www.amazon.com, www.barnesandnoble.com

ORAL, HEAD AND NECK CANCER AWARENESS WEEK
April 10-16, 2011

Plan your third party events and programs on these dates! Your efforts will increase awareness and support SPOHNC!
Contact us at 1-800-377-0928 or info@spohnc.org for more information.
# CHAPTERS OF SPOHNC

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<thead>
<tr>
<th>Chapter</th>
<th>Location</th>
<th>Contact Information</th>
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<tbody>
<tr>
<td><strong>NEW YORK-ROCHESTER</strong></td>
<td>Strong Memorial Hospital</td>
<td>Luellen Resource Center, Pat. Res. Ctr. 1st. Thursday: 4:30-6:00 PM Sandra E. Sabatka, LMSW 585-276-4529 <a href="mailto:Sandra_Sabatka@URMC.Rochester.edu">Sandra_Sabatka@URMC.Rochester.edu</a></td>
</tr>
<tr>
<td><strong>NEW YORK-STONY BROOK</strong></td>
<td>Ambulatory Care Pavilion</td>
<td>1st. Wednesday: 7:30-9:00 PM Dennis Staropoli 631-682-7103 <a href="mailto:den.star@hotmail.com">den.star@hotmail.com</a></td>
</tr>
<tr>
<td><strong>NEW YORK-SYOSSET</strong></td>
<td>NSLIJ-Syosset Hospital</td>
<td>2nd. Thursday: 7-30-9:00 PM Christine Lantier 631-757-7905 <a href="mailto:clantier@optonline.net">clantier@optonline.net</a> Mary Ann Caputo 516-759-5333 <a href="mailto:mary.ann.caputo@spoehnc.org">mary.ann.caputo@spoehnc.org</a></td>
</tr>
<tr>
<td><strong>NEW YORK-WESTCHESTER</strong></td>
<td>White Plains Hospital Cancer Center</td>
<td>2nd. Thursday: 7:00 PM Mark Tenzer 914-328-2072 <a href="mailto:tenzer1@optonline.net">tenzer1@optonline.net</a></td>
</tr>
<tr>
<td><strong>NEW YORK-ASHVILLE</strong></td>
<td>National Cancer Institute</td>
<td>Call for additional information Kathleen Godwin 828-692-6174 <a href="mailto:kgodwin@morrisbb.net">kgodwin@morrisbb.net</a></td>
</tr>
<tr>
<td><strong>NEW YORK-CHARLOTTE</strong></td>
<td>abandoned</td>
<td>3rd. Tuesday of even month: 5:00 PM <a href="mailto:meg.Turner@carolinashealthcare.org">meg.Turner@carolinashealthcare.org</a></td>
</tr>
<tr>
<td><strong>NEW YORK-ROCHESTER</strong></td>
<td>Strong Memorial Hospital</td>
<td>1st. Tuesday: 6:30-8:30 PM Linda Glorioso 419-996-5616 <a href="mailto:hjmetzer@health-partners.org">hjmetzer@health-partners.org</a></td>
</tr>
<tr>
<td><strong>NEW YORK-ROCHESTER</strong></td>
<td>Strong Memorial Hospital</td>
<td>2nd. Wednesday: 11:30-1:00 PM Richard Boucher 650-269-8323 <a href="mailto:richard.boucher@hp.com">richard.boucher@hp.com</a></td>
</tr>
<tr>
<td><strong>NEW YORK-MEDFORD</strong></td>
<td>Providence Medical Center</td>
<td>2nd. Friday: 12:00-1:30 PM Richard Boucher 650-269-8323 <a href="mailto:richard.boucher@hp.com">richard.boucher@hp.com</a></td>
</tr>
<tr>
<td><strong>OREGON-MEDFORD</strong></td>
<td>Providence Medical Center</td>
<td>2nd. Friday: 12:00-1:30 PM Richard Boucher 650-269-8323 <a href="mailto:richard.boucher@hp.com">richard.boucher@hp.com</a></td>
</tr>
<tr>
<td><strong>OREGON-THE WILAMETTE VALLEY</strong></td>
<td>Samaritan Reg Ca Ctr Library 2nd. Wednesday: 5:00-6:30 pm Lisa Nielsen 541-757-9882 <a href="mailto:HCNSurvivor@comcast.net">HCNSurvivor@comcast.net</a></td>
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<tr>
<td><strong>Pennsylvania-Harrisburg</strong></td>
<td>Health South Lab 3rd. Tues: 6:30 PM Joseph F. Bretsford 717-774-8370 <a href="mailto:jfbretsford1@mhm.com">jfbretsford1@mhm.com</a></td>
<td></td>
</tr>
<tr>
<td><strong>Pennsylvania-Monroeville</strong></td>
<td>Inter Community Cancer Center</td>
<td>Last Friday of month: 3:00 - 4:00 PM Beth Madrishin 412-856-7740 <a href="mailto:bmadrish@wpahs.org">bmadrish@wpahs.org</a></td>
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<tr>
<td><strong>Pennsylvania-Philadelphia</strong></td>
<td>Penn Med Perelman Ctr Advanced Med</td>
<td>1 W. Pavilion Pt &amp; Fam Conf Rm 1st. Tuesday: 11:00 AM-12:30 PM Tracy Lautenbach 215-662-6193 <a href="mailto:lautenbach@uphs.upenn.edu">lautenbach@uphs.upenn.edu</a> Mia Benson Smith, MS 215-662-4641 <a href="mailto:mia.bensonsmith@uphs.upenn.edu">mia.bensonsmith@uphs.upenn.edu</a></td>
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<tr>
<td><strong>Pennsylvania-York</strong></td>
<td>Apple Hill Medical Center</td>
<td>2nd. Wednesday: 5:00 PM Dianne S. Hollinger, MA, CCC-SLP 717-851-2601 <a href="mailto:dhollinger@wellspan.org">dhollinger@wellspan.org</a> Diane McElwain, RN, OCN, M.Ed 717-741-8100 <a href="mailto:dmcwelwain@wellspan.org">dmcwelwain@wellspan.org</a></td>
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<tr>
<td><strong>Pennsylvania-New Castle</strong></td>
<td>UPMC Jamerson Cancer Medical Arts Bldg Suite 104 3rd Thursday, 6:00-7:30 PM</td>
<td>Jeanie Williams, Patient Navigator Becky Rainville, RN 212-656-5870</td>
</tr>
<tr>
<td><strong>Pennsylvania-Philadelphia</strong></td>
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<tr>
<td><strong>Texas-Dallas</strong></td>
<td>Baylor Irving-Coppell Medical Center</td>
<td>2nd. Tuesday: 10:00 AM Dan Stack 972-373-9599 <a href="mailto:danstack@aol.com">danstack@aol.com</a></td>
</tr>
<tr>
<td><strong>Texas-Dallas</strong></td>
<td>Baylor Irving-Coppell Medical Center</td>
<td>2nd. Tuesday: 10:00 AM Dan Stack 972-373-9599 <a href="mailto:danstack@aol.com">danstack@aol.com</a></td>
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<tr>
<td><strong>Texas-Fort Worth</strong></td>
<td>Moncrief Cancer Resources</td>
<td>2nd. Wednesday: 3:30-5:00 PM Marla Hathcoat, LMSW 817-838-4866 <a href="mailto:marla.hathcoat@moncrief.com">marla.hathcoat@moncrief.com</a></td>
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<tr>
<td><strong>Texas-Houston/Tomball</strong></td>
<td>Tomball Regional Hospital</td>
<td>2nd. Tuesday: 12:00 Noon-1:30 PM Lynda Tustin, RN 281-401-5900 <a href="mailto:ltrustin@tomballhospital.org">ltrustin@tomballhospital.org</a></td>
</tr>
<tr>
<td><strong>Texas-McAllen</strong></td>
<td>Rio Grande Regional Hospital</td>
<td>3rd. Tuesday: 6:00 PM Stephanie Leal, MA,CCC-SLP <a href="mailto:SAL1275@aol.com">SAL1275@aol.com</a> Cheryl Lopez, MS, CCC, SLP 956-632-6426</td>
</tr>
<tr>
<td><strong>Texas-Plano</strong></td>
<td>Regional Medical Center at Plano</td>
<td>1st. Tuesday: 6:00-8:00 PM Polly Candela, RN, MS 214-820-2608 Polly.Candela@h InsurerHealthcare.org Emily J. Gentry, RN 214-820-2608</td>
</tr>
<tr>
<td><strong>Virginia-Charlottesville</strong></td>
<td>Dept. of Forestry Building, Suite 800</td>
<td>Last Thursday of month: 11:30-1:00 PM Vikki Bravo 434-982-4091 <a href="mailto:vsb4n@virginia.edu">vsb4n@virginia.edu</a></td>
</tr>
<tr>
<td><strong>Virginia-Fairfax</strong></td>
<td>Inova Fairfax Hospital Radiation/Oncology</td>
<td>2nd. Wednesday: 5:30-7:00 PM Corinne Cook, LCSW 703-776-2813 <a href="mailto:Corinne.cook@inova.com">Corinne.cook@inova.com</a></td>
</tr>
<tr>
<td><strong>Virginia-Norfolk</strong></td>
<td>Sentara Norfolk General Hospital</td>
<td>3rd. Monday: 7:00 PM Helen Grathwohl 757-487-2624 <a href="mailto:agrath3004@aol.com">agrath3004@aol.com</a></td>
</tr>
<tr>
<td><strong>Washington-Seattle</strong></td>
<td>Evergreen Hospital Medical Center</td>
<td>1st. Monday: 4:30-5:30 PMuke Jackson 425-788-6562 <a href="mailto:kilajackson@hotmail.com">kilajackson@hotmail.com</a></td>
</tr>
<tr>
<td><strong>Washington-Seattle</strong></td>
<td>Swedish Med Ctr. 1 E. Conf Rm</td>
<td>3rd. Thursday: 6:00-7:30 PM Susan (Sam) Vetto, BSN, RN, BC 206-341-1720 <a href="mailto:susan.vetto@vmmc.org">susan.vetto@vmmc.org</a> Joanne Fenn, MS, CCC-SLP 206-215-1770 <a href="mailto:joanne.fenn@swedish.org">joanne.fenn@swedish.org</a></td>
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<tr>
<td><strong>Wisconsin-Madison</strong></td>
<td>Univ. of Wisconsin Hospital and Clinics</td>
<td>1st. Monday: 4:30-5:30 PM</td>
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<td><strong>Wisconsin-Milwaukee</strong></td>
<td>Medical College of Wisconsin</td>
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<td>Medical College of Wisconsin</td>
<td>1st. Monday: 4:30-5:30 PM</td>
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**Gifts Have Been Received in Memory of Joseph Alden**

- Kathy Rey, Kathleen M. Sievers, Lorraine F. Soash
- Rebecca Fishman by Joanne Fishman, PhD
- Rodney Gwiazdon by Charles Bartlett
- Robert Klauber by Maxine Kossoff
- Dorothy Lipari by Joanne Fishman, PhD
- Joanne Fishman by Joanne Fishman, PhD
- Dorothy Linton by Janyne Swircek

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*Source: SPOHNC,* P.O. Box 53, Locust Valley, NY 11560-0053, 1-800-377-0928
SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER
P. O. BOX 53
LOCUST VALLEY, NY 11560-0053

SPOHNC Needs Your Help

We hope you look forward to receiving our newsletter as a useful source of information about Oral, Head, and Neck Cancer. Please help us better understand your needs by completing our survey below.

I want to continue to receive my copy of *News From SPOHNC* mailed via the Postal Service

**YES or NO**

I would prefer to receive the newsletter by email through my computer

**YES or NO**

(Please provide current email address.)

We need to hear from you ASAP!

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Or send an email:
info@spohnc.org

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