



S•P•O•H•N•C

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

FAST NEUTRON RADIOTHERAPY FOR SALIVARY GLAND TUMORS

GEORGE E. LARAMORE PH.D., M.D.

When most people hear the term “salivary gland”, they think of the large parotid glands located in the cheek areas on each side of the face. Besides these glands, there are other “major” salivary glands which lie under the chin—the submandibular and sublingual glands. In addition to these three main groups of “paired” salivary glands, there are numerous nests of glandular tissue known as “minor salivary glands” located throughout the upper aerodigestive tract (e.g. nasal cavity, paranasal sinuses, larynx, trachea, etc.). These glands produce a complex secretion known as saliva containing enzymes, antibodies and other protective factors. Salivary gland tumors, while relatively rare, constitute about 5-7% of all head and neck malignancies. Thus, there are about 2000 - 2500 such tumors occurring each year in the United States.

The majority of salivary gland tumors are “benign” growths termed pleomorphic adenomas, also known as benign mixed tumors. Less frequently occurring benign tumors are monomorphic adenomas and Warthin’s tumors. These tumors and other similar tumors are termed “benign” because they don’t spread throughout the body. However, they can cause serious local problems for the patient. The proper treatment for benign lesions is surgical removal although there is a role for radiotherapy in situations where there has been an incomplete resection of an already recurrent tumor. Radiotherapy also has a role in the treatment of inoperable lesions. These tumors generally present as a painless lump or mass which slowly enlarges. While the incidence of true malignancies varies with location, overall about 1/3 of salivary gland tumors are malignant neoplasms.

Malignant salivary gland tumors are comprised of a diverse spectrum of histologies which can be classified according to their malignant potential—i.e., propensity for spread. The most malignant group consists of high grade mucoepidermoid carcinomas, malignant mixed tu-

mors, adenocarcinomas, and squamous cell carcinomas. These frequently spread to the regional lymph nodes as well as to distant regions of the body through the blood stream. Adenoid cystic carcinomas have an intermediate classification in that while they are generally slowly growing, they tend to invade cranial nerves and can spread along them to the base of the brain. They also can spread through the blood stream, but distant metastases from adenoid cystic carcinomas may not clinically appear for many years after successful treatment of the primary tumor. Lymphatic spread is uncommon compared to the high grade tumors. Adenoid cystic carcinomas can also arise in the lacrimal (tear) glands and in the breast. Tumors having limited malignant potential are low grade mucoepidermoid carcinomas, acinic cell carcinomas, and the occasional low grade adenocarcinoma.

Unlike the more common squamous cell tumors arising in other head and neck sites, there is no association with tobacco or alcohol use. There is a weak association between radiation exposure and the development of these tumors and for the particular case of adenocarcinomas arising in the nasal cavity and ethmoid sinuses, there is a strong association with exposure to certain types of wood dust (as for workers in the lumber or furniture industries). Given the rarity of these tumors, most community cancer specialists will see only a handful of such cases over their careers. These tumors exhibit quite diverse behaviors which affect medical management decisions and it is best that patients with salivary gland malignancies receive treatment at major medical centers that are familiar with their treatment.

Treatment Options

The original form of treatment for malignant salivary gland tumors, particularly for those arising in the major salivary glands, was surgery as these tumors were thought to be “radioresistant” due to their poor response to radiation. It then became recognized that adjuvant radiotherapy given after a surgical resection of the bulk of the tumor improved local/regional control—especially when the surgery had achieved “clear resection margins”. A review of the literature shows that the local control rate is increased from 55% to 76% when postoperative radiotherapy is used after a “complete” total excision of tumor; unfortunately, there was no accompanying improvement in survival. In the case of large tumors, extensive surgery often causes the patient a great deal of morbidity—especially if it were necessary to sacrifice the facial nerve as may be the case for parotid tumors. Although modern surgery has made great strides in terms of nerve grafting procedures, there is often a residual weakness on the involved side of the face. In cases where the graft doesn’t “take”, the paralysis could be complete. Conventional radiotherapy alone is not the answer, since a review of about 300 patients treated with conventional x-ray therapy alone showed local control rates of only about 24%. Because of this poor outcome and the fact that salivary gland tumors had a relatively superficial location, these tumors were among the first to be treated with fast neutron radiotherapy.

NEUTRON 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

Linda K. Clarke, MS, RN, CORLN Greater Baltimore Medical Center	Herman Oliver, M.D., F.A.P.A. North Shore-LIJ Health System
David W. Eisele, MD University of California San Francisco	David G. Pfister, M.D. Memorial Sloan-Kettering Cancer Center
Keith Heller, M.D., F.A.C.S. North Shore-LIJ Health System	Jed Pollack, M.D. North Shore-LIJ Health System
Alex Keller, M.D., F.A.C.S. North Shore-LIJ Health System	James J. Sciubba, D.M.D., Ph.D. Johns Hopkins Medicine
Jesus E. Medina, MD University of Oklahoma Health Sciences	Elliot W. Strong, M.D., F.A.C.S. Memorial Sloan-Kettering Cancer Center
Eugene N. Myers, M.D., F.A.C.S. University of Pittsburgh School of Medicine	Denise M. Vey Voda, M.A., D.D.S North Shore-LIJ Health System
David Mysiorek, M.D. North Shore-LIJ Health System	David P. Wolk, M.D., F.A.C.S. North Shore-LIJ Health System

Karrie Zampini, CSW
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

Facial Lymphedema and Physical Therapy.....4
A Time For Sharing.....6

COMING IN SUMMER, 2002
The Effects of Hyperbaric Oxygen
Robert E. Marx, D.D.S.

NEUTRON continued from page 1

Neutron Radiotherapy: Basic Facts

What is a neutron? The neutron was discovered by Sir James Chadwick in 1932. It is a heavy, uncharged particle that is found in the atomic nucleus. It has about 1839 times the mass of the electron. Neutrons are created by accelerating heavy, charged particles such as protons or deuterons (nuclei of heavy hydrogen) to energies in the range of several tens of million electron volts and then impacting them onto a suitable target such as beryllium. These nuclear reactions take place which produce neutrons. Complex instruments such as cyclotrons or particle accelerators are used to accelerate the protons or deuterons and these instruments are much more expensive and require more technical support than the devices used to produce X rays and/or electrons in standard radiotherapy centers. Neutrons interact directly with the atomic nuclei in the tissue deposit 20-100 times more energy along their path than do x-rays or electrons. This gives them different radiobiological properties—some of which may lead to better tumor control. In particular, tumors are not able to repair radiation damage from neutrons as easily as they can the damage caused by conventional x-ray or electron treatments.

Early Treatment Results

The first treatment facilities were very primitive by modern standards but nevertheless, an amazing amount of clinical research was carried out on many different tumor systems with varying degrees of success. The best results of all were obtained for salivary gland tumors. A survey of the literature showed a total of about 300 patients with salivary gland tumors treated with x-rays with a local control rate of about 24%. A similar group of about 300 patients treated at the early neutron therapy centers showed a local control rate of 67% — more than double that of the x-ray treated group. To verify these results, the Radiation Therapy Oncology Group (RTOG) in the United States and the Medical Research Council (MRC) of Great Britain jointly conducted a randomized trial comparing neutron and x-ray treatments for salivary gland malignancies. This trial was stopped early for ethical reasons when 2-year data became available. At two years the local control rate was 67% for the neutron group compared to only 17% for the x-ray group; the respective survival rates were 62% vs. 25%. The investigators felt it proper to offer neutron radiotherapy to all appropriate patients. With longer follow-up times for the patients entered into this study, there continued to be improved local control in the neutron group (at 10 years 56% vs. 17%) but there was ultimately no long-term survival advantage due to distant spread of tumor.

Deaths due to distant metastases became a more important factor with patients living longer due to better local tumor control. The patients treated on this study all had very advanced tumors and these distant metastases likely were present in undetectable amounts at the time of the original treatment. The exact mechanism through which neutron radiotherapy achieves better local control in salivary gland tumors is not well understood but it may relate to these tumors being able to repair much of the damage caused by ordinary types of radiation. Radiation damage due to neutrons is not as readily repaired by tumor cells.

Modern Neutron Radiotherapy in the US

Based upon the results of these and other studies, the National Cancer Institute funded the design and construction of neutron radiotherapy centers to be placed directly in hospitals and devoted primarily to patient treatment. Four such units were constructed but due to design and opera-

NEUTRON continued on page 3

NEUTRON from page 2

tional problems, only one of these is still functioning. This is the center located at the University of Washington Medical Center in Seattle, Washington. The majority of patients currently treated at this facility have salivary gland tumors with advanced prostate cancer and sarcomas of bone and soft tissue being other tumor types for which neutrons seem to offer a more effective form of treatment. At the present time there are only two other operating radiotherapy centers in the United States—a superconducting cyclotron located at Harper-Grace Hospital in Detroit, Michigan, which mainly emphasizes the treatment of prostate cancer and a laboratory-based treatment facility utilizing a proton accelerator at the Fermi National Laboratory in Batavia, Illinois.

The hospital-based, neutron radiotherapy centers in Seattle and Detroit are considerably more sophisticated than the earlier treatment units and results are commensurately improved. One study from the University of Washington evaluated 52 different patients with salivary gland tumors generally arising in the major glands and divided them into 3 groups: one group treated with neutrons alone (no prior surgery), another group treated after a surgical resection which left behind significant amounts of tumor, and a third group treated for growing tumors recurrent after a previous surgical procedure. The group treated with neutrons alone did best of all with a 92% local control rate at 5 years compared to 63% for patients treated postoperatively for gross residual disease and 51% for patients treated after a clinical recurrence. This is a small number of patients but the data seems to indicate that a radical surgical procedure, perhaps with sacrifice of the facial nerve, may not be necessary if neutron radiotherapy is available. Another paper from the University of Washington focused on patients with adenoid cystic carcinomas of the major and minor salivary glands. Twelve year local control was about 45% for patients with gross disease at the time of treatment; in a group of 8 patients who had only microscopic disease at the time of treatment, there were no local failures. Another review from the University of Washington of 148 patients with major salivary gland tumors of all malignant histologies showed a 5-year local control rate of 80% for tumors less than 4 cm in size.

Pleomorphic Adenomas

Another situation where neutrons seem to be beneficial is for patients with multiple-recurrent,

benign, pleomorphic adenomas of the parotid gland. Only a limited number of high risk patients with inoperable, multiple-recurrent tumors have received neutron radiotherapy to date. Unpublished analysis of 16 such patients shows a 15-year actuarial local control rate of 85%. Unlike malignant tumors, these lesions do not rapidly regress after treatment but soften and then gradually involute over a period of years.

Side Effects of Treatment

As with any form of radiation therapy, neutron radiation causes side effects such as sunburn-like skin reactions, soreness in the mouth and throat, difficulty swallowing, dry mouth and altered taste sensation. There can also be increased scarring of the tissues in the cheek and neck. Individualized treatment planning can reduce but not eliminate these effects which can in some cases be worse than for x-ray therapy due to the increased energy deposited by the neutrons along their paths. Agents such as Saligen can often improve salivary gland function resulting in an acceptable saliva output. We are also studying the use of amifostine to protect tissues during radiotherapy, but it is not clear that this agent will protect against neutron radiation to the same extent it does against conventional radiation. Because of the intense mucositis reaction caused by neutrons, we often recommend placement of a PEG tube (feeding tube placed directly into the stomach) particularly in the older patient. About a 10-15% incidence of hearing loss on the treated side has been noticed in patients treated for tumors of the parotid glands.

Logistics of Fast Neutron Radiotherapy

What can a patient seeking neutron radiation for a salivary gland tumor expect? Using the University of Washington treatment center as a model, the following sequence of steps takes place:

1. The patient, upon arrival in Seattle, is formally evaluated with a comprehensive history-taking and physical examination and an immobilization mask constructed with the patient in the same position as will be used during treatment.
2. A special CT scan for treatment planning is obtained with the patient in the mask and the information from this scan fed directly into a treatment planning computer.
3. Correlations may be made between these images and MRI and/or PET studies.
4. Appropriate radiation fields are designed and these often are modified during treatment in or-

der to maximize the neutron dose delivered to the tumor and minimize the neutron dose to the surrounding normal tissues.

5. A complete 3-dimensional model of each patient's tumor and surrounding tissues is studied on the computer in order to optimize their particular treatment.

6. The treatment course itself consists of 16 separate treatment sessions scheduled over 4 weeks. The treatments themselves are painless and take only about a half hour per day.

Summary

Fast neutron radiotherapy centers are a unique resource for patients with salivary gland tumors. Neutron radiotherapy is probably not necessary for the majority of patients with these tumors. In almost all cases, patients with benign tumors should be treated initially with surgery. Even malignant tumors that are small and superficially-located can be treated conventionally with surgery and possibly postoperative radiotherapy. It is those patients with large or deeply situated tumors where a complete surgical resection is either not possible, or if possible, would result in a great deal of morbidity who should be referred for neutron irradiation. This would include patients with recurrent tumors after an initial surgical procedure and possibly even after failing conventional x-ray postoperative treatments. There are probably around 500 such cases per year and with proper triaging, the majority of these patients can be treated at the three existing centers. Most insurance companies recognize the efficacy of neutron radiation in such cases and pay for patient treatment. Unfortunately, the costs of travel and living expenses in most cases must be borne by the patient. ■

Editor's Note: George E. Laramore is Professor and Chair of Radiation Oncology at the University of Washington School of Medicine. He is board certified in Therapeutic Radiology and his current research interests lie at the interface between physics and medicine.

References

1. Laramore, G.E., Krall, J.M., Griffin, T.W., Duncan, W., Richter, M.P., Saroja, K.R., Maor, M.H., Davis, L.W.: Neutron vs. photon irradiation of unresectable salivary gland tumors: Final report of an RTOG-MRC randomized clinical trial. *Int. J. Radiat. Oncol. Biol. Phys.* 27: 235-240, 1993.
2. Buchholz, T.A., Laramore, G.E., Griffin, B.R., Koh, W.-J., Griffin, T.W.: The role of fast neutron radiation therapy in the management of advanced salivary gland malignant neoplasms. *Cancer* 69: 2779-2788, 1992.
3. Douglas, J.G., Laramore, G.E., Austin-Seymour, M., Koh, W.-J., Stelzer, K., Griffin, T.W.: *Int. J. Radiat. Oncol. Biol. Phys.* 46: 551-557, 2000.
4. Douglas, J.G., Lee, S., Laramore, G.E., Austin-Seymour, M., Koh, W.-J., Griffin, T.W.: Neutron radiotherapy for the treatment of locally advanced major salivary gland tumors. *Head Neck* 21: 255-263, 1999.

Facial Lymphedema and Physical Therapy: What You Should Know

TERRANCE A MCKEON, P. T., C.D.T.

Lymph is a fluid that circulates in special channels throughout the body. It consists of water, white blood cells, cellular debris, and protein rich matter. The lymphatic system includes the series of channels responsible for transporting the lymph back to the circulatory system. Along the way, lymphatic tissues, such as the lymph nodes, help filter the lymph and trap or eliminate potentially harmful material.

The lymphatic tissues also produce white blood cells (lymphocytes) that are vital in fighting bacteria and viruses. These lymphocytes are a crucial part of the immune system. There are lymphatic channels in, and immediately below, your skin. They cover the whole surface of your body. These channels are very tiny, very close to one another and form a lymphatic plexus or network.

The plexus acts as a sponge to soak up and gather lymph fluid. The fluid is dumped into deeper channels called collectors. Lymphatic collectors are much like veins in that they are vessels with one-way valves that travel to the heart. Collectors carry lymph instead of blood. Just like veins, collectors follow a typical pattern that can be traced. They also have smooth muscle in them, which allows them to contract and to move lymph fluid. All smooth muscle responds to stretch by contracting.

Secondary Lymphedema

Treatment of oral and head and neck cancer may include the surgical removal of a tumor and the nearby draining lymph nodes and vessels. Such surgery may result in blocking lymph fluid from flowing naturally through the lymph system. This secondary lymphedema can occur immediately in the post-surgical period or several weeks or years later.

Radiation therapy, used in the treatment of oral and head and neck cancers, can also damage otherwise healthy lymph nodes by causing scar tissue to form in them and in the normal lymph pathways (collectors) and lymph plexus areas. Furthermore, the radia-

tion can cause a skin burn on the area being treated, which may initiate the secondary lymphedema.

Lymphedema can occur secondary to an infection (called cellulitis) that interrupts normal lymphatic function. If a patient has already had surgery or radiation his or her lymphatics may be compromised but still compensating effectively. Any small interruption of this delicately balanced compensation could result in lymphedema. This is why preventive measures are so important for the post surgical patient. It is important to monitor the area for any skin changes, such as inflammation or blistering.

Even though there may not be any symptoms, a patient having had surgery and/or radiation to the head and neck area, may be "walking on thin ice" as the lymphatics now must work much harder, possibly at 100% instead of 10% to keep up with the lymph that is being produced. As one might expect, the lymphatic capacity (LC) may gradually decrease as a result of being overworked until the lymph system can no longer deal with the lymphatic load. At this point, one is said to have lymphedema.

A person in a situation such as this will notice swelling on some days and not on others. If left untreated, the lymphatic capacity (LC) will continue to drop from being overworked and the condition may worsen. Depending on the extent of surgery, and the anatomy of the individual, the condition may advance faster if an additional injury, or an infection occurs, thus resulting in a rapid progression of the swelling.

Symptoms Related To Lymphedema

- Chronic cellular changes can predispose someone to recurrent infections. These changes will often raise the temperature of the involved area. Each infection not only damages lymphatics further, and can be very painful, but can also pose a serious overall health threat.
- Facial Lymphedema can decrease facial

mobility causing minor functional impairments such as difficulty with speech and swallowing, hindered eyesight, and pain and discomfort due to stretching of the skin.

- Lymphedema may cause embarrassment and may lead to depression. In particular, facial edema is visible and cannot be hidden from the public eye.
- In patients with extreme lymphedema, the accentuated asymmetries lead to tendonitis and biomechanical problems such as chronic neck pain, headaches, and difficulty with speech and swallowing.
- When lymphedema first occurs it will pit if pressed with a thumb. As the limb becomes larger and harder, it no longer pits. The tissue feels thick and can feel like it is bursting or aching.
- Lymphedema can also affect the joints and muscles of affected limbs leading to achy pain that often feels like "arthritis" or muscle soreness.
- Leaking lymph fluid may be present and will predispose the area to infection and wounds or to delayed healing from surgery.

Manual Lymph Drainage (MLD)

Manual massage-like techniques are designed to shift the lymphatic fluid from congested areas to normal ones. Because the lymph vessels are so close to the skin, the techniques are very light. These techniques also stimulate the weakening parts of the lymphatic system by pushing the stagnant fluid through the vessels, allowing the venous system to reabsorb the fluid and help develop collateral channels through which the lymph can begin to flow. Manual lymphatic drainage also stretches the skin, which is beneficial in the following ways:

- The collectors react to the stretch by reflexly contracting at a faster rate because they have smooth muscles in their walls.
- The openings of the lymphatics are stretched to allow more fluid to enter. This phenomenon occurs because the plexus cells are anchored to the skin by filaments, which

move when the skin moves. In this way, lymphatics work better and those which are dormant are utilized more effectively.

Determining the Direction of MLD

Fluid can be moved in any direction over healthy skin using the plexus (network). Because the plexus is like a sponge this process can be slow. Use of healthy collectors also occurs, taking advantage of the numerous collaterals, or emergency pathways, our body normally has to compensate when injured. The order and direction of MLD depends on the patient's history. Light, skin stretch massage is first done on healthy lymph nodes and vessels creating a suction effect. Then on the affected side as well as intra-oral techniques. A patient can be taught to perform self massage.

Postural Drainage

Gravity affects fluid movement and collection so practical advice on positioning is given such as:

- Putting blocks under the head of the bed to raise it. (1-2 feet) Do not just put pillows under your head as this will lead to neck pain. Sleeping in a Lay-z-Boy may help to so long as your head is above your heart however such a posture may lead to hip flexion tightness.
- If one side is more involved than the other never lay on that side. Lay on the non-involved side.

Compression

Compression options are difficult with facial edema and don't always work well. However, they are worth trying and sometimes are invaluable. These options include:

- Bandaging with short stretch bandages, which are sometimes combined with various types of foam. Even if only temporary or for short periods of time, when bandaging is done properly, it can help break up fibrosis (thickening) in tissues as well as reduce the volume of edema and improve esthetics.
- Special Skin Tape called Kenesiotex can sometimes help stretch and pull the skin and encourage better flow of edema. Some people do not respond well and have reactions to the tape; therefore, caution should be exercised. Do not use skin tape over skin that is healing or has been significantly damaged by radiation. A test run on your arm is a good idea to

check for reactions.

- Simply resting your hand on your involved chin or area periodically is some form of helpful compression.
- Many garments can be custom made to wear during sleeping or for periods of time to add compression in the face.

Exercise

Along with exercises given to most patients who attend speech therapy, other exercises of the face and neck prove invaluable in improving biomechanical function, and in softening the tissues under the skin. If still in tact post surgery, deep muscles of the neck (especially the scalene and Hyoid muscles) are often weak and tight and need to be exercised and stretched.

- Exercise in the pool is excellent for lymphedema. Lymph flow increases while in water. This has been demonstrated in numerous studies.
- So called "facial gymnastic exercises" such as making funny faces, emphasizing the expression of emotions, yawning, reading out loud with deliberate enunciation and purposeful movement of the mouth, and chewing gum are some examples of good exercise. No exercise should be done excessively as this may lead to more lymph production. Check with a therapist for advice.
- Deep breathing exercises can be extremely helpful as well. Yoga type exercises such as sun salutations (excluding down dog), or "fire breathing" help to create a great suction effect into the thorax towards the heart where all lymph fluid eventually drains at the "venous angles of the heart."

Skin Care

Exceptional skin care and hygiene are important in lymphedema to help avoid infections and wounds. Use of a low PH lotion daily such as Eucerin or Curel is helpful in this regard, as well as close monitoring and treatment of any cuts or abrasions.

Benefits-What to expect from treatment

As the history and causes for any one individual's set of symptoms varies widely, so too does ones outcome after physical therapy treatment. Benefits that may or may not be received from therapy include:

- Improvement of facial asymmetry due to lymphedema.
- Softening of tissues
- Decrease in the hypersensitivity of the area making it easier to tolerate touch and clothing on the neck.
- Improved range of motion
- Decreased pain caused from muscular imbalance, hypersensitivity, or edema.
- Tools for ongoing self maintenance, (garments, self -massage, exercise, education)

Risks

As the therapy is very non-invasive, the risks are minimal, if any. You may experience a temporary increase in painful symptoms when introduced to the exercises, or to the scar tissue massage if needed. Scar tissue massage is a friction type of massage that is done over scars that are bound down to the tissues below and hindering comfortable and normal functional movement.

Summary

Lymphedema of the head and neck is a common complication of head and neck surgery, especially when combined with radiation. Symptoms vary depending on the extent of surgery and ones individual anatomy and healing capability and anatomy. Some of these symptoms may be minimized by introduction of physical therapy measures such as MLD, Compression, Skin Care, education and positioning, and Exercises. The risk of such therapy is very low.■

Editor's Note: Terrance A. McKeon, P.T. is a Canadian trained physical therapist with over 10 years experience at Queen's University, Kingston, Ontario. He began specializing in the treatment of lymphedema 7 years ago and is recognized nationally in the USA as one of the leading clinical instructors for certifying therapists in the treatment of lymphedema. He currently practices and teaches through Kessler Lerner Lymphedema Services Needham, MA.

For further information, please contact:
Greater Boston Support Group
<<http://kynosoura.com/lsg>>
Kessler Rehabilitation
<www.kessler-rehab.com>
Kessler Rehab (Needham, Ma)
1-800-232-5542 (Terry McKeon, P.T.)
National Lymphedema Network
<www.lymphnet.org>

A TIME FOR SHARING

Amifostine? I wondered why the drug was important enough to merit a call from a parishioner of my mother's church in January 2000. The caller was a cancer patient who participated in a successful clinical trial of Amifostine and strongly recommended it to protect salivary glands and mucous membranes of the throat and mouth during head and neck radiation. He knew about my diagnosis of squamous cell carcinoma (SCC) of the tonsil, Stage 4 with metastasis to the lymph nodes and my modified radical neck dissection. He suggested that some salivary function might have already been lost. I was skeptical about this new drug as its effectiveness can vary. It can also be quite toxic, and, in my case, it required a major last minute adjustment to my treatment plan. Would it work for me and was it worth the risk of side effects in addition to those from radiation?

My new friend indicated that amifostine might reduce severe dry mouth after radiation, even though success rates varied and there were problems with scheduling and toxicity. His certainty that amifostine had saved his salivary glands from irreversible radiation damage and helped him regain much of his sense of taste convinced me to request the drug. I could barely imagine what the loss of my salivary glands could mean, and consequently, I asked my oncologist about the drug. She agreed to include it in my treatments despite a chance that a positive outcome was not assured. Thus in January 2000, I became the first patient at my hospital of choice to receive amifostine. The FDA had approved the use of amifostine only a short time before. I was indeed relieved to learn that my medical insurance would cover the drug as the cost can be as much as \$15,000.00.

Each treatment began at about noon in the infusion lab where the infusion department MD and nurses checked my vital signs, levels of pain, nausea, vomiting, sleep patterns, and gastrointestinal condition, etc. Five days a week for 7 weeks, I received amifostine piggybacked with my daily 2 liter IV drip to maintain blood pressure and hydration. Fully reclining sofa chairs made relaxation easier as I received a new IV line daily. (Overnight temporary lines invariably blew out at home) I really appreciated the expertise of the nurses

who set the IVs daily, usually on the first try with little pain or bruising. What a magnificent skill!

Following my treatment, I immediately walked to the radiation department to begin my radiation therapy. For maximum results, patients should be radiated within 10-15 minutes of receiving amifostine. The drug's effectiveness is compromised if more than 30 minutes pass before radiation begins. It is not fully understood how it works, but in clinical trials, amifostine dramatically improved saliva output after radiation when compared to patients who did not receive the drug. I was fortunate to learn of the drug and be approved for this new treatment. However, there are side effects that many people may experience. These side effects included a drop in blood pressure when the drug is administered, and

...All things considered, having the option to include amifostine in my cancer treatment plan was very fortunate; so too, was the timely advice from a fellow patient, connected to me only by faith.

severe nausea and vomiting, as well as other more rare side effects. The risk of a sudden drop in blood pressure from amifostine led to close monitoring of my vitals as the medication was administered. The risk was also minimized by having me relax, recline and remain hydrated continually prior to radiation. Toxicity was also a concern for me, but at the age of 48, I was considered strong enough to handle it.

I felt reassured by the personal care I received as my physical condition gradually deteriorated over the weeks. I experienced no serious side effects for the first 10 days. The infusion lab and the radiation therapy department had to coordinate my care to provide me timely radiation immediately after I received amifostine. I was gratified by the team effort on my behalf in both departments, as I was their pioneer amifostine patient. Eventu-

ally the daily walk to radiation grew more difficult until I was truly frightened by my declining energy levels. My oncologist and related staff I worked with me and guided and supported me through the crisis of my life as we balanced aggressive medical treatments with my ability to tolerate the strain physically and emotionally. I shall forever be grateful for their expertise and especially their efforts to make me as comfortable as possible, as the side effects became severe.

The combination of radiation and amifostine was taking its toll on my body dramatically. Despite trying many medications, nausea and vomiting precluded any meaningful oral nourishment and I lost weight rapidly. I was overwhelmed and miserable and lost almost thirty pounds. I feared that treatment would have to be interrupted as I gradually became so weakened that I needed assistance walking. (It should be noted that the severity of nausea and vomiting due to the amifostine varies greatly from patient to patient but can now be controlled more effectively in many cases after more experience with the drug) It was difficult to be sure if my complications were due to the amifostine or not, but it was clear that the combined treatments made me very ill.

It was indeed fortunate for me when a nurse, who worked overtime to help me throughout my amifostine treatments, suggested that I try concentrated oil of peppermint to relieve my debilitating nausea. Miraculously it worked! Just a drop dabbed on my nostril every hour or so gave me almost complete relief! I carried the tiny bottle with me everywhere for many months thereafter. The peppermint oil was a blessing, and very helpful during radiation therapy. Not all patients respond to this form of aromatic therapy, but it worked for me and marked a critical point in my physical stabilization. Nevertheless, I was not able to eat solid food for 5 more months due to a severe sore throat from radiation. Consequently, I had a PEG tube inserted to halt the weight loss. I kept the PEG for another year.

I completed my course of amifostine and radiation without interruption but radiation caused problems in my mouth, tongue and throat. I had no sense of taste and had great difficulty swallowing. My mouth was extremely

SHARING continued on page 7

SHARING continued from previous page dry immediately after radiation ended and moistening my mouth with fluids was a constant and stressful battle for the next 6 months. My throat was also badly scarred and almost totally dry and my voice was very hoarse. For months I doubted that the amifostine treatments had accomplished anything as I had very little measurable saliva.

While reading about dental care I learned that artificial sweeteners promote salivation. I tested that assertion about 4 months post radiation with a stick of sugarless gum and to my astonishment my mouth filled with thick saliva in only a few minutes! My salivary glands worked after all; they just needed stimulation! A few days and many packs of gum later I realized amifostine had protected my salivary glands more than I ever imagined. The mucous membranes in my mouth and throat were damaged by radiation but eventually returned to a near normal state. I believe that my recovery was aided substantially by preserving delicate oral tissues and salivary glands due to amifostine. In particular my battle with dry mouth was frustrating and slow but critical tissue was preserved.

More than eighteen months have passed since I discovered how to stimulate my saliva and I am currently 2 years in remission from cancer and optimistic about my recovery. Whereas I once planned my day around water fountains, juice boxes and iced tea to avoid that frantic feeling from constant dry mouth, I now have near normal amounts of saliva, albeit a bit more thick in consistency. I keep fluids handy to promote oral comfort but it is not a source of anxiety for me any longer. My tongue feels more moist and I rarely experience dry mouth, unless I eat

overly dry foods. I still enjoy the feel of cooling drinks in my mouth, especially with meals.


My sense of taste has returned very slowly, even though some foods remain unappealing to my taste. I use (and recommend) Biotin products to aid with mouth care and oral hygiene.

In retrospect, meaningful recovery from dry mouth, even with the help of amifostine, can take several years. But any reduction of dry mouth is worth the challenge of tolerating this drug during a treatment program. The key in my treatment may well have been preserving tissue from the most extreme damage. Patience is required, to put it mildly.

I am grateful to have my life back, albeit on different terms and to once again enjoy my family and friends, and yes, to work again. I could not have made it through this ordeal without the care and support of my loving family and true friends. The quality of medical treatment I received was exceptional and especially comforting emotionally at every turn. I am grateful to be alive. All things considered, having the option to include amifostine in my cancer treatment plan was very fortunate; so too, was the timely advice from a fellow patient, connected to me only by faith. ■

Chuck Lane
Charlottesville, VA

Comment: Studies are currently being conducted with head and neck cancer patients to investigate alternative methods of administering amifostine including subcutaneous injection and rapid IV.



Helping to Build Awareness of Oral and Head and Neck Cancer

SUPPORT SPOHNC
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

Visa, Mastercard and American Express accepted by phone and mail
Visa and Mastercard accepted at www.spoHNC.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+

PHONE #
 404-284-8045
 561-395-7100
 617-731-1703
 732-356-1 CO
 972-373-9599
 703-698-2813
 281-259-4110
 800-377-0928
 631-585-1121
 212-288-5718
 708-327-2147
 305-596-6566
 305-243-4952
 973-586-3522
 856-722-5574
 402-559-2814
 412-647-9127
 760-751-2109
 202-784-3755
 414-454-5631
 503-413-7834
 410-828-2087
 614-293-6428
 718-780-1801
 212-717-3527
 215-707-4924
 773-702-6611
 734-936-6037

COORDINATOR/FACILITATOR
 Harmon Grotsky
 DarcI Lipson-McNally, LCSW
 Valerie Goldstein
 Bernadette Maszczak
 Dan Stack
 Pam Black
 William A. Phelan
 Nancy Leupold
 Alice Peters
 Barney Phair
 Thom De Vries, LSW
 Blanche Bronwit
 Penny Fisher, RN
 Howard Sakolsky
 Micki Naimoli
 Robert Bayer, RN
 Marilyn Hudak, RN
 Valerie D. Targia
 Joanne Assarsson
 Kathy Myers, RN
 Carol Ross
 Linda Clarke/Lynne Delancey
 Kimberly Ann Holle
 Lorelee Fulton, RN
 Karrie Zampini
 Stefanie Washburn
 Sidney Munson OSW
 Tammi Miller, RN

SPONSOR
 SPOHNC-ATLANTA, GA
 SPOHNC-BOCA RATON, FL
 SPOHNC-BOSTON, MA
 SPOHNC-BRIDGewater, NJ
 SPOHNC-DALLAS, TX
 SPOHNC-FAIRFAX, VA-Heads Up
 SPOHNC-HOUSTON, TX
 SPOHNC-LONG ISLAND, NY
 SPOHNC-LONG ISLAND, NY-East (now forming)
 SPOHNC-MANHATTAN, NY
 SPOHNC-MAYWOOD, IL-Loyola (now forming)
 SPOHNC-MIAMI, FL
 SPOHNC-MIAMI, FL-Mort Silverblatt Head and Neck
 SPOHNC-MORRISTOWN, NJ
 SPOHNC-NJ-PA
 SPOHNC-OMAHA, NE-UNMC
 SPOHNC-PITTSBURGH, PA
 SPOHNC-SAN DIEGO, CA
 SPOHNC-WASHINGTON, DC-LCC
 Froedert Cancer Center (Milwaukee, WI)
 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)
 University of Michigan Hospitals (Ann Arbor, MI)

HEAD AND NECK CANCER SUPPORT GROUPS IN THE UNITED STATES



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

Have you renewed
 your membership in SPOHNC?
 Please check the date on the
 address label of your newsletter
 and renew your membership
 to receive our newsletter
News From SPOHNC
 You can now renew
 your membership by
 credit card
 CALL 1-800-377-0928
 or
 Renew online at www.spohnc.org