



**S•P•O•H•N•C**

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

## LINGERING EFFECTS OF HEAD AND NECK CANCER AND ITS TREATMENT

BRUCE H. CAMPBELL, MD, FACS

Cancer survivors are a special group of people. Almost nine million people in the US today are survivors; most are over 65. The vast majority of cancer survivors have been treated for breast, prostate, bladder, female genital, colon and rectum, blood, or lung cancers. Head and neck cancer survivors make up a much smaller proportion of the US cancer survivor population, but about 20,000 more people are added to their ranks each year. Research is just beginning to probe the issues that are important to survivors. Nevertheless, cancer and its aftermath continue to be felt long after cancer treatment has finished with many of the long-term problems being poorly understood.

A story...

I recently talked to a survivor who bitterly complained about the dryness in his mouth. "Doc, they can put a person on the moon, but you can't fix my dry mouth. Why is that?" At each visit, he sits in the exam chair glumly holding a half empty water bottle. The cancer is gone, but the radiation therapy destroyed his ability to make saliva. Every night, he wakes up two or three times to take a sip of water, and he gripes that he can't get a good night's sleep. His sense of taste is shot, he has trouble chewing, and he needs a glass of water in order to swallow almost anything. He would give anything to have enough moisture to eat a slice of bread or some crackers!

The man's complaint brought to mind research conducted by Dr. Marcy List at the University of Chicago. Dr. List found that when newly diagnosed head and neck cancer patients are asked to

list the things that they most hope for from their treatment, the top three concerns are "being cured," "living long," and "living pain free." Less than ten percent of new patients mention any concern about the possibility of trouble with "chewing," "being understood," "taste," or "dry mouth" (J Clinical Oncology 2000; 18:877).

When survival itself is at stake, what rational person worries about seemingly trivial problems such as oral dryness or loss of taste? Each type of cancer and its treatment has its own constellation of potential long-term problems. It strikes me as sadly ironic that the very concerns that are the least worrisome when treatment begins often develop into the most bothersome months and years later.

Future oral cavity cancer survivors will probably have fewer dryness problems thanks to increasingly sophisticated radiation therapy techniques. For the survivors in my practice, though, the dryness will forever be a nagging aggravation and each meal reminds them anew of the diagnosis that many would rather forget.

Early Effects v. Late Effects

"Early effects" are changes that are seen at the time of treatment or in the early post-treatment weeks. These can include swelling, skin breakdown, loss of lining membranes, numbness, pain, loss of taste, nausea, vomiting, exhaustion, and the other problems that are well known to cancer survivors. "Late effects" are those that develop or continue long after treatment has been completed. Examples of "late effects" are tightening of scars, persistent loss of movement or sensation, thinning of muscle and lining tissues, persistent dryness, and persistent psychosocial effects. Many survivors complain of a "drawing" sensation of the tissues of the neck and face. Over the past few years, studies have demonstrated that most of the early effects are at their worst just as treatment has been completed but they tend to improve over the next 12 months. Some of the effects persist, however, and these become the "late effects."

Measuring the Effects

In order to understand the long-term effects of cancer treatment, we invited 86 of our five-year cancer survivors to participate in a battery of tests that included taking measurements of voice and physical activity as well as responding to questionnaires concerning quality of life. Nineteen other survivors who were unable to come in for measurements completed the questionnaires, only.

The survivors' original cancers had been located in the larynx, oral cavity, and oropharynx. A smaller number of survivors had cancers of the pyriform sinus. Most had been treated with radiation therapy alone or surgery followed by radiation therapy. A smaller number had been treated with surgery alone or radiation followed by surgery. Only two survivors had received chemotherapy.

EFFECTS continued on next page



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**IN THIS ISSUE**

A Time for Sharing.....4  
 Radiation/Surgery and Trismus.....5  
 National Chapters of SPOHNC.....6

**COMING IN SEPTEMBER, 2003**  
 Fine Needle Aspiration of Neck Masses  
 Jonas T. Johnson, MD

**EFFECTS continued from page 1**

reflecting the practices in place at the time when these particular survivors had been originally treated. In the future, more and more survivors will be dealing with the long-term effects of chemotherapy because of its increasing use in the treatment of head and neck cancer.

**Cancer Stage**

Survivors of advanced stage cancers were more likely than survivors of early cancers to indicate that they felt “disfigured” and were “unwilling to eat in public.” Not surprisingly, the advanced stage survivors underwent more extensive treatment than the early stage survivors.

**Cancer Site**

Interestingly, in our group of survivors, the original location of the cancer did not have an impact on their long-term quality of life. For example, survivors of oral cavity cancer had no better or worse quality of life scores than survivors of laryngeal cancer.

**Swallowing and Weight Loss**

The ability to swallow successfully had a significant impact on long-term quality of life. X-ray swallowing studies showed that many of the survivors continued to have difficulty with swallowing even simple liquids. A significant number of survivors continued to have aspiration, or the passage of food and barium into the voice box instead of the esophagus. Survivors who continued to demonstrate some aspiration were found to have weight loss (a mean loss of 22 pounds) and problems with swallowing efficiency. Survivors who showed no signs of aspiration tended to have no significant change of weight from before their cancer treatment.

**Dryness**

Each of the survivors underwent measurement of how much saliva they could produce. Not surprisingly, some could produce none at all. Survivors with less saliva were found to have more difficulties with swallowing efficiency. Since the dryness was associated with the amount of radiation therapy that had been given to the major salivary (spit) glands, the higher the radiation dose to the salivary glands, the less saliva the survivor could make.

**Teeth**

The presence or absence of useful teeth had a significant impact on the survivors’ perception of their own quality of life. Survivors whose dental condition had deteriorated or who had few useful teeth had higher scores on scales measuring their pain perception and sense of disfigurement. These survivors also noted more problems with chewing, swallowing, and the ability to be understood. Survivors who had difficulty with opening their mouth widely reported more problems with chewing and swallowing, and they were much less willing to eat in public.

**Shoulder Function**

Survivors who had undergone any type of neck dissection had decreased shoulder quality of life scores and shoulder range

EFFECTS Continued on page 3

EFFECTS continued from page 2

of motion measurements. Modified neck dissections (preserving the main nerve to the powerful trapezius muscle) showed relatively better movement; however survivors who had no required neck surgery at all had the best shoulder function. Survivors whose shoulder movement was diminished reported more problems with pain, a higher sense of disfigurement, and lower activity levels. These survivors reported being less functional than survivors whose shoulder movement was better.

#### Psychosocial Function

In a previous research project, we had found that some of our cancer survivors were more concerned about the possibility of their cancer recurring than were other survivors. In this study, survivors who were found to have strong problem solving skills tended to be less concerned whether their cancer might return. Problem solving skills also were associated with better quality of life scores and overall function, in general.

#### Tobacco and Alcohol Use

Almost 90% of our survivors had smoked, although some had quit before their cancer was diagnosed. Approximately 25% had stopped smoking well before cancer treatment and 30% quit at the time of their treatment or soon thereafter. However, approximately 35% of the cancer survivors continued to smoke five or more years after diagnosis. Those who continued to smoke were less likely to say that tobacco had caused their cancers than those that were not smoking. People who smoked also were found to be more likely to have heavier alcohol use histories.

We found that about 65% of survivors who had smoked had now quit completely. Approximately 30% of those who had ever used alcohol had quit. We routinely work with our cancer survivors to quit smoking because we know that quitting can improve health. However, we do not know whether it would be important for us to recommend to our cancer survivors that they stop using alcohol.

#### Improving quality of life.

This group of cancer survivors demonstrates what head and neck cancer survivors face everywhere. Many of the

effects of cancer treatment last for years and years after the completion of treatment. Physicians in the last few years have developed modifications of “standard” treatments and entirely new treatments which hopefully will lessen some of the long-term “late effects.” For example, as surgeons, we are working harder to preserve tissues and restore contours during cancer treatment. Fewer radical neck dissections are done now than were done a generation ago. The newer surgical techniques are designed to preserve shoulder function and neck appearance. More patients are offered “organ preservation” treatment that attempts to control cancer without removing the larynx or mandible. Radiation oncologists have developed newer techniques that spare parotid tissue and hopefully will diminish long-term dryness problems. Medical oncologists are testing newer drugs and treatments that may have fewer long-term side effects. Even these innovations, no doubt, will have consequences down the road. We will depend on our surviving patients to notice the problems and point them out. Only then will we be able to develop strategies to study and control the side effects.

#### Intervention

What can we do once the “late effects” have developed? Continuing evaluation by a speech and language pathologist can help identify swallowing problems and offer advice to improve understandability and swallowing efficiency. Dental rehabilitation, although extraordinarily expensive for most survivors, can have a significant impact in long-term quality of life, willingness to interact with others, and willingness to eat in the presence of other people. Problems with shoulder function need to be addressed with continued physical therapy and exercises.

Smoking cessation remains a critically important issue for cancer survivors. People who have had cancer should work hard to quit and also encourage friends and family members to quit with them. Research several years ago indicated that survivors who continue to smoke have a higher rate of new cancers. It is less clear how hard to push survivors to abstain from alcohol. It is clear, however, that alcohol

is a promoter of head and neck cancer and heavier alcohol users (that is, people who have more than one or two drinks per day) are at risk for many other diseases.

Psychosocial issues are poorly understood in head and neck cancer survivors. Approximately 20% of head and neck patients had some evidence of depression at the time of diagnosis and problems with depression can continue for years. Psychosocial adjustment is difficult for many survivors and can require intervention by a psychologist or psychiatrist.

Over the past years, I have been privileged to interact with many head and neck cancer patients, survivors, and family members. The quality of survival can depend a great deal on the quality of the relationship that is established between the survivor and the people who provide care. From my personal experiences with my patients, I have learned that the optimal quality of life after cancer treatment assumes that the cancer survivor reaches a point of both cure and healing.

#### Changing Priorities

Fortunately, the National Cancer Institute established the Office of Cancer Survivorship in 1996 with an emphasis on understanding the problems faced by Americans after being treated for cancer. As more patients become cancer survivors, these issues will have an even greater impact.

The “late effects” of cancer treatment on head and neck survivors can be significant and longstanding. However with therapy and the passage of time, some of these effects do become better tolerated and understood. Over the past few years, quality of life research has become an important part of every major cancer treatment protocol. The data obtained from this research will allow us to better understand how to provide healing as well as cure in the future.

This research was supported by a grant from the National Cancer Institute (R01 CA78940). The project was conducted at the Medical College of Wisconsin by a research team led by Bruce Campbell, MD, Peter Layde, MD, MSC, Katherine Myers, RN, and Anne Marbella, MS.

*Editor's Note: Bruce Campbell, MD is Professor of Otolaryngology and Interim Director of the Cancer Center at the Medical College of Wisconsin. MCW is located in Milwaukee. Dr. Campbell can be reached via email at bcampbel@mcw.edu*

## A TIME FOR SHARING Jon Allan's Birthday Party

Sometimes the happiest of events are freighted with an undercurrent of sadness. That was the case with the celebration of my son Jon's fiftieth birthday in March. A little over a year earlier he had been diagnosed with squamous cell carcinoma. Surgery revealed that the primary site was on his left tonsil and that cancer cells had penetrated lymph nodes in his neck. After a miserable summer going through chemotherapy and radiation to his neck, which involved a PEG tube for placing nourishment directly in his stomach, by winter he was able to swallow and eat normally again. Christmas was great, but New Year's was awful. On the last day of 2002 he learned that a CT-scan showed cancer in lymph nodes in the left axilla (armpit).

Another surgery removed lymph nodes, but the pathology showed that the vascular system was also involved. The prognosis was grim, nevertheless after consulting with his doctors he decided to have radiation therapy in the new area and to save chemo for a time when organs might be affected.

Usually neck cancer is associated with older people who have a history of smoking and drinking. Jon has never smoked and his imbibing was limited to rare beer drinking. He is 6'4" and has always been athletic. His general good health and physical fitness, as well as an easy going personality, no doubt have helped him in withstanding intensive treatment; it has also placed him in a category of unusual cases for which very little research has been done. In surfing the internet for any and everything related to neck cancer, he found SPOHNC, which came to play an important role in his birthday celebration.

As Jon finished radiation in February his birthday was approaching, and his wife, Elizabeth, and I decided that a good party was in order. Planning it became a cheering project in which Jon fully participated. We found a beautiful setting within the Portland, Oregon, area where Jon and his family, as well as his father and I, live. A hillside estate, built early in the 20th century, has been taken over by the local park district and turned into gardens and meeting facilities. The renovated

barn was our choice for the site as it's large enough to accommodate the hundred plus guests we intended to invite and also, is charming. It retains its first identity, with large open spaces plus the original (but thoroughly cleaned!) stalls and even a tin lined trough that can be loaded with ice and beverages. A Western theme was the obvious choice for decorations as well as for dinner which was catered by an excellent barbecue restaurant.

The date for the party was Saturday, March 22nd, three days after his actual birthday, in order to accommodate those who were coming from long distances. What made the event so joyful was having relatives and friends coming from afar, many of whom hadn't been together in years. Jon's and Elizabeth's entire families are both large. Jon's three siblings and Elizabeth's four siblings plus her mother and all the offspring of the siblings came from California, Washington, and Oregon. Jon's and Elizabeth's children include Jon's young adult daughter, a student at Chapman University in Orange, California, and a nineteen year old son, Elizabeth's twelve year old daughter, and their own six year old son, all of whom were actively involved in the party. Cousins from Minnesota, Maryland, and North Carolina made the trip. The guest who made the longest trip was Jon's French "brother," a foreign exchange student who lived with us in 1968-69 and has been close ever since, and who is now a psychiatrist living in Tarascon, in Provence.

Jon and his sister and two brothers grew up in China Lake, California, a Navy research base in California's Mojave Desert where Wally, their father and my husband, was a physicist working on the Navy's airborne missiles. One of our family's main activities was the local swim team which not only provided wonderful swimming expertise for its members, but also a lively social life. The coach was more than a coach; she was a mentor and friend, so fond of her charges that she was like a surrogate mother. She and her husband, who have been in contact with our family ever since those years, came to the party, as did four of the team swimmers. Then

there were colleagues from Jon's working past as an engineer. Finally, there were the neighborhood friends who have been unbelievably supportive and helpful during Jon's illness. Everything, from child care to house and yard upkeep to dog-walking, to daily meals, they generously and cheerfully provided. It was truly heart-warming to see that old barn filled to the rafters with so many loving people.

Needless to say, the festivities lasted for the entire weekend. The Beaverton Hilton Garden Inn was headquarters for most out-of-towners and became the setting for something of a house party. Wally's and my home was also a gathering place where food and drink as well as entertainment by two tiny children (our great-granddaughters) were always available. On Sunday morning, Jon and Elizabeth hosted a post-party luncheon for the visitors at a lovely city owned recreation house in Lake Oswego. Then it was time to say good-byes, some tearful and all affectionate. Anti-climatic blues were lessened, however, by having Olivier, our French connection, remain for the next week. He and Jon enjoyed some private time together, and Wally and I enjoyed outings with him, especially one to some nearby wineries where Olivier could indulge his wine connoisseurship in trying Oregon's famous pinot noirs.

When Jon mailed the invitations to the party, which he had designed and produced, he requested that in lieu of gifts, he would like guests to make donations to SPOHNC. The sight of 120 people almost all wearing SPOHNC pins was impressive indeed. The amount of money raised may not fund any research, but it wasn't insignificant. More important, all of us whose lives he has enriched are now aware of a terrible illness that isn't yet well understood or effectively treated. Our fervent hope is that Jon will live to see definite progress in overcoming oral, head, and neck cancer.

*Lois Allan,*  
Beaverton, OR

## Have You Had Radiation/Surgery for Head & Neck Cancer?

In some cases, one side effect of radiation treatment or surgery can be limited mouth opening. This condition, often referred to as 'trismus', can become a long-term problem, if not treated properly and promptly.

### *What causes trismus?*

Trismus is caused by damage to the muscles used for chewing. Surgery or radiation therapy may cause damage to these tissues that result in scar tissue formation. Scar tissue and other damage can combine to make it difficult to open your mouth.

### *Why is this a problem?*

Reduced mouth opening can make it difficult to eat, clean your teeth, or speak. These difficulties can occur at a time when proper nutrition, and oral hygiene are particularly important to your recovery.

Proper nutrition is especially important at a time when you are recovering from surgery, chemotherapy, or radiation treatment. At this time, you need all the energy you can obtain, and proper nutrition is fundamental to your recovery.

Oral hygiene is particularly important during and immediately after radiation treatment, as you may be at high risk for cavities from radiation itself as well as from xerostomia, (dry mouth). If you are unable to open your mouth sufficiently to brush your teeth, you are likely to have trismus or developing this condition.

The ability to speak can be affected by limited mouth opening.

### *How can I tell if I have this condition?*

The simplest way to test for trismus is to insert three fingers between your front teeth. If you can do this, you are probably fine. If not, you may have trismus.

### *What is likely to happen?*

Trismus is unlikely to get better on its own with the condition slowly worsening over time. Treatment for the condition is relatively simple, if diagnosed and treated early. As in many conditions, delaying treatment can make the process longer and more difficult.

### *What can I do?*

Trismus is generally treatable if treatment is begun within several months of radiation treatment or as soon as opening difficulties arise. Studies have found that the

use passive motion can have a positive effect on trismus. However, it is important to begin treatment as soon as possible. Individuals who begin treatment early are more likely to obtain a better result, and may invest less time and effort in the recovery process than those individuals who delay treatment.

### *What else is going on?*

In addition to the obvious change in opening of the mouth, it is important to realize that limited motion of the mouth also has an effect on the joints and muscles used to eat and speak. Joints that are not moved through their range of motion on a regular basis are likely to degenerate. Similarly, muscles that are not used regularly, will become weaker and fatigue more easily.

These changes show that it is important to undertake a rehabilitation regimen that addresses all of these issues. The goal of treatment should be to stretch connective tissue, mobilize the joints, and strengthen muscles of mastication and opening.

### *Why is motion better than simple stretching?*

In the past, tongue depressors were often prescribed to help improve mouth opening. However, a number of clinical studies have found that tongue depressors are not as effective as passive motion and stretching to reverse the effects of trismus. This may be due to the fact that tongue depressors, which assist in a prolonged static stretch, cannot help in mobilizing the joint, or strengthening muscles.

In a clinical trial of individuals who had already developed trismus, it was found that persons using passive motion improved more than three times as much (13.6mm over a ten week period) than did individuals using tongue depressors (3.5mm over a ten week period). This trial was conducted at Mt. Sinai School of Medicine. The results of this trial have been repeated at other universities.

If trismus is a problem for you, your doctor or therapist can explain the alternatives available to you, and help you decide which is best for you. These alternatives may include static stretching with tongue blade stacks in combination with physical therapy with a range of motion component as well as commercially available devices designed to combine passive motion and static stretching.

For more information, please call 414-227-2333 or visit [www.therabite.com](http://www.therabite.com).



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**Irwin Ellerin, Esq**  
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and  
**Gary Hillerich, Esq**  
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*for their assistance and support  
following the death of his wife, Phyllis.*

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2nd Monday, 6:30-8:00 PM  
Contact: Harmon Grotzky, 404-284-8045  
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Emory University Hospital  
Last Monday, 6:30-7:30 PM  
Contact: Arlene Kehir, RN, 404-778-2196  
Email: Arlene\_Kehir@emory.org

SPOHNC-BOCA RATON, FL  
Davis Out-Patient Rehab Center  
1st Tuesday, 3:00-4:00 PM  
Contact: Darci Lipson-McNally, LCSW  
561-395-7100; Email: DMcNally@brch.com

SPOHNC-BOSTON, MA  
Massachusetts General Hospital  
3rd or 4th Tuesday  
Contact: Valerie Hope Goldstein  
617-731-1703; Email: Fernval@aol.com

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Somerset County Library  
2nd Wednesday, 6-7 PM.  
Contact: Bernadette Maszczak, 732-356-1939  
Email: bernadetteM@webtv.net>

SPOHNC-CHARLOTTE, NC\*  
Blumenthal Cancer Center  
2<sup>nd</sup> & 4<sup>th</sup> Thursday, 1:30-3:00 PM  
Contact: Meg Turner, 704-355-7283  
Email: megturner@carolinashhealthcare.org  
Contact: Terri Painchaud, 704-364-7119  
Email: trappi6@hotmail.com

SPOHNC-COLUMBUS, OH-JCC\*  
James Cancer Center  
1st Monday  
Contact: Vicki Heinke, MSW, 614-293-7042  
Email: heinke-1@medctr.osu.edu

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The Cvetko Center  
2nd Tuesday, 11:00 AM-1:00 PM  
Contact: Travis Maxwell, 214-820-2608  
Contact: Jack Mitchell, 972-496-6561  
Email: jackmitchell5225@aol.com  
Contact: Pam Hess: 972-234-0943  
Email: Pam@hess-family.org

SPOHNC-DALLAS, TX  
Baylor Irving-Coppell Medical Center  
2nd Saturday, 10:00 AM  
Contact: Dan Stack, 972-373-9599  
Email: danrstack@aol.com

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ACS Office, Conference Rm. A  
Brooks Bldg, 2253 S. Oneida St.  
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Department of Otolaryngology, 37  
Research Way, Stony Brook NY.  
1st Thursday 7:00-9:00 PM  
Contact: Fran Tanzella, 631-444-7678  
Email: Ftanzella@notes.cc.sunysb.edu

SPOHNC-LOS ANGELES, CA-UCLA  
UCLA Medical Plaza  
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Contact: Sabah Qasim, LCSW, 310-825-5707  
Email: SQasim@mednet.ucla.edu  
Contact: Pam Hoff, LCSW, 310-825-6134  
Email: hoff@radonc.ucla.edu>

SPOHNC-MANHATTAN, NY  
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Email: robblou@aol.com

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Email: tdevrie@lumc.edu

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Contact: Blanch Bronwit, 305-596-6566

SPOHNC-MIAMI, FL-Mort Silverblatt Head &  
Neck Support Group  
Sylvester Comprehensive Cancer Center  
1st & 3rd Monday 1:00-2:00 PM  
Mort Silverblatt; Coordinator Emmeritus  
Contact: Penny Fisher, RN, 305-243-4952  
Email: pfisher@med.miami.edu  
Contact: Marty Mash. 301-594-8993  
Email: msamash@myacc.net

SPOHNC-MORRISTOWN, NJ  
Carol B. Simon Cancer Center  
3rd Wednesday 1:30 PM  
Contact: Howard Sakolsky, 973-586-3522  
Email: hesakolsky@aol.com

SPOHNC-NJ-PA  
UPENN Hospital  
Penn Tower, 10th Fl., Philadelphia  
1st Wednesday, 9:30-11:00 AM.  
Contact: Micki Naimoli, 856-722-5574  
Margaret Lazer, 215-349-8388

SPOHNC-OMAHA, NE  
University Medical Center  
3rd Friday 3:00-4:30 PM  
Contact: Robert Bayer, RN, 402-559-2814  
Email: rbayer@unmc.edu>

SPOHNC-ORANGE, CA-UCI  
UC Irvine Medical Center  
Associates Conference Room  
1st Monday, 6:30-8:00 PM  
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Email: baker@uci.edu>  
Contact: Jennifer Higgins, MSW  
714-456 8609 Email: jhiggins@uci.edu  
Contact: Linda Kraje: 562-691-7657

SPOHNC-PITTSBURGH-PA-UPMC  
Montefiore Hosp., Unit 11, N. Conf. Rm.  
1:00-2:00 PM (Call for day of week.)  
Contact: Marilyn Hudak, RN, 412-647-9127  
Email: hudakme@msx.upmc.edu>

SPOHNC-SAN DIEGO, CA  
Contact: Valerie Targia, 760-751-2109  
Email: valtargia@yahoo.com

SPOHNC-SAN FRANCISCO, CA-UCSF\*  
UCSF Comprehensive Cancer Center  
1<sup>st</sup> Thursday, 4:00-5:15 PM  
Contact: Barbara Buckley, LCSW  
415-885-7623  
Email: barbara.buckley@ucsfmedctr.org

SPOHNC-TOMS-RIVER, NJ\*  
Community Medical Center  
Last Thursday of the Month; 3:00-4:00 PM  
Contact: Sherry Laniado, MSW, LCSW  
732-557-8270 <slaniado@sbhcs.com>

SPOHNC-WASHINGTON, DC-LCC  
Lombardi Cancer Center.  
Podium A, Conference Room  
3rd Monday, 12:15-1:45 PM..  
Contact: Joanne Assarsson, LICSW  
202-784-3755  
<assarssj@gunet.georgetown.edu>

\*New chapters in 2003

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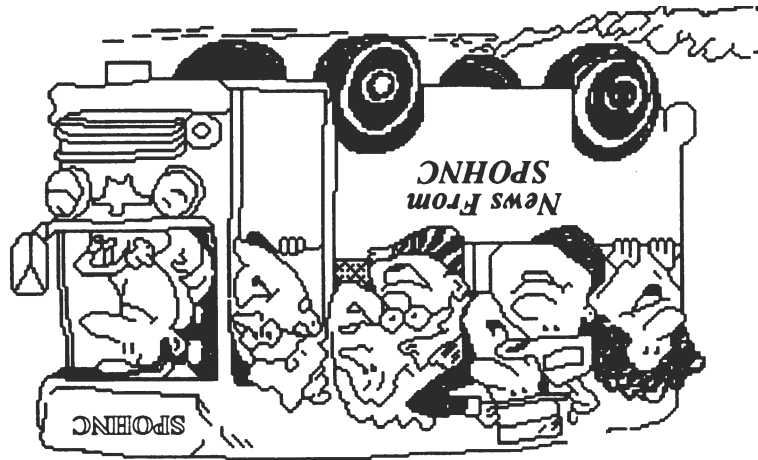
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