



**S•P•O•H•N•C**

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

## **SPEECH AND SWALLOWING FUNCTION AFTER TREATMENT FOR CANCER OF THE LARYNX**

JAN S. LEWIN, PH.D.

Cancer of the larynx primarily affects individuals in the sixth and seventh decades of life. Less than 1% of cases occur in individuals below the age of 30 years. In 2003, an estimated 9,500 new cases of laryngeal cancer diagnoses were anticipated in the United States accounting for approximately 7% of the 1.3 million cases of cancer in adults, excluding carcinoma in situ, and basal and squamous cell cancers of the skin. Although the male-to-female ratio for laryngeal cancer in the United States is approximately 3:1, the incidence among women is increasing. Cancer of the larynx is one of the more curable cancers of the upper aerodigestive tract, with an estimated 5-year survival rate of 68%, however, this rate has not changed significantly over the past 25 years. Despite a good prognosis for cure, the side effects from available treatments continue to affect quality of life. Therefore, the focus of current research has been to evaluate and improve the quality of life after treatment for cancer of the head and neck.

A variety of treatments are currently available for the management of cancer of the larynx. The range of options continues to evolve as we attempt to determine the optimal method or combination of methods to improve quality of life and increase survival rates. It is only recently that our investigations have focused on evaluating post-treatment functional outcomes (speech and swallowing) using scientific methods. Therefore, we are just beginning to understand the true impact of cancer treatments on speech and swallowing and their long-term effects. However, for patients with advanced cancer of the larynx, the selection of treatment has become much more complex. How to identify patients who will survive longer and have a better functional outcome after conservative organ preservation treatments of combined radiation and chemotherapy and which patients are best treated with surgical removal of the larynx, remains unclear.

The first goal of cancer treatment is to cure the cancer; the second goal is to preserve or restore function. Radiation therapy is the most common alternative to surgery in the treatment of cancer of the larynx. Another option is chemotherapy that is combined with either surgery or radiation therapy to improve outcome. In recent years, surgical procedures that remove the cancer but preserve all or part of the larynx (partial laryngectomy) have become widely used. Because this type of surgery conserves the larynx, it is known as conservation surgery. Some early-stage vocal cord cancers can even be removed in an outpatient surgical procedure using a carbon dioxide laser. Patients who receive this treatment usually recover quickly and have few related side effects. For patients with early stage cancer of the larynx, radiotherapy or conservation laryngeal surgery results in excellent outcomes, both in terms of survival and function. The problem comes about when there is more advanced disease with other significant problems, which may affect the patient's ability to tolerate even temporary complications such as the aspiration of food. Also, combined treatments with chemotherapy and radiation that spare the larynx but leave the patient unable to swallow or speak normally may prove less desirable than surgery. Given the current advances in technology and rehabilitation, removal of the larynx (total laryngectomy) often produces better functional outcomes and quality of life than do treatments that spare but cripple the larynx.

Patients in whom treatment has failed or whose cancer is so advanced that partial laryngectomy, radiation therapy, and chemotherapy are not options for cure are best treated by total laryngectomy. Conservation treatment approaches are associated with a significant risk for long-term complications such as aspiration, permanent tracheostomy, and inability to produce voice. Total laryngectomy, on the other hand, is associated with a high potential for excellent postoperative speech and swallowing and few associated complications, and therefore, is frequently the treatment of choice.

Radiation therapy (or radiotherapy) may be used alone or in combination with chemotherapy, surgery, or both to treat laryngeal cancer. However, it often results in immediate and long-term changes in speech and swallowing. In general, radiotherapy affects swallowing more than it does speech. The addition of chemotherapy can intensify these effects. Because the effects of radiation increase with successive treatments and may continue long after radiation treatment has been completed, radiotherapy may harm speech and swallowing function as much or more than surgery does.

The magnitude of problems associated with radiation therapy will frequently depend upon the radiation dose that is given, the duration of treatment, the size of the treated area and whether chemotherapy was also used. For most patients undergoing radiotherapy, the normal reaction of the irradiated tissue is usually swelling, redness, and irritation. Patients undergoing radiotherapy frequently experience pain, which exacerbates swallowing problems and may limit the patient's ability to eat and drink enough to maintain oral intake. Controlling the pain may be the key factor to being able to eat by mouth and thus helps to avoid the need for a

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tube in the stomach to maintain nutrition during and after radiotherapy. Patients undergoing radiotherapy may experience early improvement in speech and swallowing followed by deterioration of these functions. This often signifies radiation-induced changes in tissue. Healthcare providers may be fooled by the early improvement in both speech and swallowing after the initial swelling has resolved. However, it is not uncommon for speech and swallowing function to deteriorate several months to years after the completion of radiotherapy. This decreased function is often caused by the formation of fibrous tissue or scarring of surrounding muscles, which restricts laryngeal movements, impairs vocal fold closure and may reduce the range of motion of the tongue and jaw. Patients often report difficulty swallowing, with food being caught in the throat as a result of impaired movement through the pharynx. Aspiration is a common complication in patients who have been treated with radiation. Many patients who are treated with radiation therapy can benefit from referral to speech pathologists and other rehabilitation specialists, who can create an exercise plan designed to strengthen and increase range of motion, precision, and muscle elasticity and mobility. When these exercise plans are started early, patients experience overall improvement in speech and swallowing.

**Rehabilitation**

Cancer of the larynx (and cancer of the head and neck in general), presents many challenges to speech pathologists and other rehabilitation specialists to achieve the best functional outcomes for the patient. Because the treatment is so complex and the potential for complications so high, a strong multidisciplinary team made up of specialists from many fields who work together allows the patient to benefit from the unique expertise of each team member. This critical aspect of patient care cannot be overemphasized. Patients should meet with all members of the interdisciplinary team before their head and neck cancer treatment begins. Pretreatment measurements of speech and swallowing abilities are essential for later evaluation of post-treatment function to ensure patient satisfaction and optimal quality of life. The counseling provided by a knowledgeable speech pathologist regarding post-treatment changes provides realistic patient expectations for recovery and encourages the patient to actively participate and take responsibility in an aggressive rehabilitation program. Pretreatment counseling gives the patient an opportunity to ask questions and to better understand information that is often overwhelming and frightening, thus reducing the fears and misconceptions associated with the cancer and the selected treatment. The current level of scientific knowledge, the availability of a variety of treatments for patients with head and neck cancer, and the nearly universal ability of patients to access information via the Internet and media make the demand for state-of-the-art multidisciplinary care even greater. As such, intervention must begin early.

Although the goal of any cancer management is first and foremost cure with the additional goal of eradicating the tumor, patients with head and neck cancer experience treatment-related effects that can substantially impair both speech and swallowing, ultimately reducing quality of life. Thus, both physicians and patients should consider post-treatment function while planning and deciding upon the patient's cancer treatment. Early referral to a speech pathologist who has expertise in the rehabilitation of patients with head and neck cancer is critical for successful functional outcome.

*Editor's Note: Jan S. Lewin, Ph.D. is Associate Professor and Director of the Speech Pathology and Audiology Section in the Department of Head and Neck Surgery and Director of the Voice Laboratory at the University of Texas M.D. Anderson Cancer Center.*

## FIRST ANNUAL SPRING 5K WALK



Saturday, April 24, 2004 was the first annual Spring 5K Walk in Ann Arbor Michigan. The goal of this event was to raise awareness of oral and head and neck cancer and to support programs of SPOHNC which benefit oral and head and neck cancer survivors.

Twenty-six walkers, one biker, and three dogs showed up for the 3 mile walk at Gallup Park. Participants received SPOHNC information, newsletters, awareness ribbons, and cards indicating how to recognize signs and symptoms of oral and head and neck cancer. Upon finishing the walk, participants also enjoyed beverages, muffins, and received t-shirts. Survivors were recognized with red roses. Linda Foley and Dolores McDole, who planned this year's event, look forward to improving and expanding it next year.

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## NATIONAL SURVIVOR VOLUNTEER NETWORK ACTIVATED

On Wednesday, April 21, 2004, with the support of an educational grant from AstraZeneca Pharmaceuticals, SPOHNC held its first Volunteer Training workshop for its National Survivor Volunteer Network (NSVN). AstraZeneca had also co-sponsored the first phase of the National Survivor Volunteer Network along with MedImmune Pharmaceuticals and Aventis Pharmaceuticals. Phase one enabled SPOHNC to compile and distribute materials necessary for the project.

Nancy Leupold, an oral cancer survivor and president and founder of SPOHNC, was the moderator of the Volunteer Training teleconference. To better acquaint the participants with the organization, Nancy gave some background information about SPOHNC including how and why she founded the organization in 1991.

Following Nancy's presentation, Janine Cortese, the network administrator, explained

that the National Survivor Volunteer Network developed out of a need to respond to the many calls and emails that SPOHNC was receiving asking to speak with or email someone with a similar experience to their own. Not being able to handle all the calls and emails "in-house," Nancy felt that the best people to respond to survivors would be other survivors who had similar experiences and were well on their way to recovery.

Consequently, last October, SPOHNC asked for volunteers to help in this endeavor. More than 100 survivors and caregivers from 33 states responded. These individuals were sent a rather in-depth application to enable Janine to match them appropriately with a caller or someone emailing the SPOHNC office. While waiting for the applications to come in, Janine and Nancy compiled a great deal of information for the volunteers and with the help of a memorial gift, they were also

able to put the information on a CD.

Of the more than 100 applications that were distributed, 75 applications have been received to date. Once the applications were received and Janine and Nancy saw the enthusiasm of the volunteers wanting to help others, they mailed out the binders containing hard copies of information, as well as the CD and "We Have Walked In Your Shoes," a three part packet of information for patients. As the volunteers perused the material in the binder, Janine and Nancy planned the teleconference which was held on April 21st.

This was truly an informational workshop followed by a question and answer period. Fifty of sixty eligible volunteers participated in this first training session.

Ms. Maida Cherry, was the guest speaker for the teleconference. Ms. Cherry has 15 years of experience working with volunteers in a non-profit environment, creating volunteer programs and training volunteers. Until recently, she was Field Services Coordinator for the Sjogren's Syndrome Foundation, a national organization providing telephone support and local support groups to people with Sjogren's Syndrome, an autoimmune disease. Ms. Cherry is the founder and past president of the Association of Professional Volunteer Administrators (APVA). The APVA is a group of Long Island professionals that provides education, networking and support to administrators of volunteer programs in a variety of settings.

During the teleconference, Ms. Cherry spoke about the characteristics of effective peer counseling and provided the participants with much information that they can apply to their roles as Survivor volunteers and representatives of SPOHNC in their communities.

At the conclusion of Ms. Cherry's presentation, participants were encouraged to ask questions. This was an informal period during which many good questions were asked and answered.

At the conclusion of the training session, NSVN was activated to match volunteers to survivors in need of support. SPOHNC is pleased to see a such a strong network developing to help, support and encourage others. Good communication between survivor volunteers and SPOHNC will help ensure that SPOHNC is meeting the needs of oral and head and neck cancer patients and helping to raise awareness of a rare disease.

## A TIME FOR SHARING...It's a Wonderful Life

It is a beautiful spring morning here in Columbus, Ohio. A day that makes one feel thankful, joyful and truly blessed. I have celebrated several important events recently—another birthday and my thirty-first wedding anniversary are on that list. But the biggest milestone I am celebrating is that this year, 2004, is my twentieth year of being cancer free!!

My cancer journey has been a life changing one, to say the least. Twenty years ago I noticed a red, sore area along the left side of my tongue. Even to this day I've never had a cold sore or canker sore. So this was very unusual for me. Not being a smoker or drinker, I didn't think it too serious. But I knew that one cancer sign is "a sore that doesn't heal." This area did not improve over the next two weeks. Since my educational background includes nursing, I listened to the RN in me and made an appointment with a doctor. I remember seeing the horrified look on his face during the exam and hearing him say a biopsy was needed as soon as possible. I think I knew then that my "sore spot" was cancer. Within a few days, an oral surgeon performed the biopsy. Soon the pathology report came back as squamous cell carcinoma of the tongue.

Sitting in the exam room with the oral surgeon and my husband, my only thought was, "What do we do now?" At that time we lived in a small town, population under three thousand, with very limited medical facilities close by. I was thirty-two years old, with two young children ages three and seven, and a husband still in the early phases of his position as a college professor. I felt the situation hopeless. I was scared for me, my husband, and most of all my children. All I could do was sit there, listen, ask questions and cry. The oral surgeon emphasized that for my best treatment outcome I needed to be seen by expert surgical oncologists at a major comprehensive cancer center. He had already made an appointment for me at The Ohio State University Medical Center, one hundred miles from our home.

I felt so numb, unable to function. I remember crying as we called our relatives five hundred miles away and told them the news. Crying and hugging my children as we told them I needed to see more doctors about fixing my sore tongue. Crying as I called our friends from church and asked them to pray for us. I was so upset I couldn't even

concentrate enough to pray. In retrospect, I know the decision to ask for prayer was probably one of the best things I could have done at the time. My relationship with God has been a big part of my life, even as a child. Of course, our faith experience changes as we go through life. I do believe that all of us are spiritual creatures, though we may or may not believe in a divine being. I best know God as a Spiritual Presence in and around all of us; a wonderful gift of love, acceptance, and strength that I especially needed to have during this horrible time. And gradually after that request for prayer, I did start to feel calmer. I was able to pray and ask for wisdom and confidence in decision making for both me and the doctors. Strangely enough, I have never ever asked God to be healed of cancer. And to this day, I don't know why that is.

Soon after meeting my surgical oncologist at OSU, I had the tumor and part of my tongue removed, leaving "clean margins" around the site. After ten days in the hospital, I traveled the one hundred miles home to heal. Of course, twenty years ago treatment plans were much different. I had no reliable CT, MRI, PET scans, or sentinel node techniques to look for metastasis. No feeding tube, no Ensure or Boost, no support group, no speech therapist to help with learning to swallow and talk again, no other tongue cancer patients to talk to. I was alone. The only thing I did know was that I had a fifty percent chance of recurrence. I was afraid to even ask about making it to the five year mark. Post-op treatment for me was not recommended at that time since tissue changes caused by radiation therapy would make further surgery, if needed, very difficult. I kept my frequent appointments with the surgeon, continued to examine my mouth and neck in between office visits, and waited. Within four months, I was facing a diagnosis of metastasis to the lymph nodes in my neck. I immediately called my surgical oncologist when I noticed a lump just a few days after he had examined me thoroughly. I had not beaten the odds. So we again prepared our little family for another stay in the hospital. I underwent a modified radical neck dissection followed a month later by intensive radiation therapy over about an eight week period.

Twenty years later, I am continually amazed and grateful for how my life has developed. I've heard patients say that "cancer

is one of the best things that ever happened to me." I will never say that is true for me. But I WILL say I have had the chance to learn things (some happy, some sad) about myself, family, and friends, and experience God's presence in ways I would never have known otherwise. It has truly changed me.

I know now there is a period of grieving all cancer patients go through. We (especially oral, head, and neck cancer patients) look and feel differently. We eat and speak differently. The "old me" is gone forever. Personal relationships may change. And even post-treatment, a certain amount of anger and denial continues as we struggle in getting on with life, wanting to take up where we left off but finding life is not like it was before. And you know what? It's OK to be pretty ticked off about that!!

Loss of control was a real issue for me. The realization was frightening. Of course, we don't really control everything in our life at all. I've come to see that as a true gift. What a terrible burden—to be totally responsible for every aspect of our life, not only our own actions and events both good and bad, but also the resulting consequences for others. There I was; an active, healthy, young woman suddenly betrayed by my body when it developed tongue cancer. I had become so tired and so sick that I couldn't eat, talk plainly, or do the most routine things to care for my family. Would I even live to see our youngest enter kindergarten or our oldest begin middle school? Why me? Now my answer to that is, "Why NOT me? Cancer is an equal opportunity disease."

I am so thankful an inner "something" kept me going—kept me trying to find a better way to live, to be the most complete person I could be. And I know it is God's continuing Spiritual Presence giving me the strength, courage, and imagination to do what needs to be done. That's what being a survivor means to me. It has nothing to do with being disease free. It has everything to do with how I live my life. I can't control the fact that I've had cancer, but I can control my response to it.

I've learned to accept help from others. I tend to be the "Little Red Hen" type, to do it myself. And of course it's always "better to give than receive". But I've come to realize that learning how to thankfully receive allows others to learn how to give. During my radiation treatments, someone (I still don't know who) arranged for a driver to be outside our door every morning to make the one

hundred mile trip to Columbus and then back home. Others provided food and care for our children, or just came to be with us. This allowed my husband to carry on with his teaching responsibilities during the day. Of course, some friends I thought would surely help never came or called. I now know they just couldn't handle it.

I've gained many more new friends along the way. I especially remember the college students who collected spare change to help with gas money during our many trips to the doctor; and others who came to help with the clean-up chores around our home. However, the one chore I always insisted on doing myself was our laundry. I don't know why—maybe something about the cleansing aspect of it all. I still laugh when I think about it. I had become so weak by the end of radiation treatments that my husband had to carry the clothes to the washer and dryer. All I had strength to do was push the “on” button, but I HAD to be the one to do it. I don't know what I thought would have happened if my Maytag bond would have been broken, but I sure didn't intend to find out!

I've become a stronger advocate for myself and my family. Cancer is a family disease. Our oldest child, then a second grader, had an especially rough time of it. Kids are very perceptive and know, even at age seven, that cancer kills people. They see a loved one go each day for treatment and come home even more ill. Children know that doctors are supposed to make people feel better. So why was Mom getting sicker? Our son's reaction was just to sit in school, quiet and teary eyed, unable to put his fears into words. I feel very fortunate that I was able to find a counselor for us that specialized in working with children of ill parents. Also, my surgeon was very thoughtful and kind, taking time to explain things to our son in terms he could understand.

Today I'm thankful that emotional support for children of cancer patients is recognized as a real need. Wonderful opportunities for education and support of patients, their caregivers and children are now available at the cancer center where I was treated. More are needed at medical facilities everywhere. And kid friendly indoor/outdoor spaces with books, toys, and play areas separate from in-patient hospital rooms would give children visiting their ill loved ones the time and place to be together as a family in a more normal setting.

I know the importance of taking care of myself first in order to heal and again be a help to others. I try to listen to my body and

feed my spirit, continuing some habits from before cancer and adding new ones along the way. All have led me to feel more empowered over cancer. During the past twenty years this has come to include prayer and meditation, a healthful diet, regular checkups with my physicians and dentists, resting when I feel tired, walking for exercise, therapeutic massage, planting a garden, making time for fun with family and friends, “pilgrimages” to Wrigley Field for Cubs baseball, lots of music, lots of laughter, attending the Support group for People with Oral, Head and Neck Cancer (SPOHNC) now available in my area, cheering on the OSU Buckeyes, continuing to ask questions, looking for sources of reliable information, a silly hobby of collecting pigs, learning to do massage for the lymphedema in my face, meticulous dental hygiene, and hard work with a psychologist at various points along the way.

One of the lowest times for me was just a few years ago. I've had many bouts with cellulitis, lymphedema and facial pain, along with more hospitalizations and surgery. (Cancer is the “gift” that just keeps on giving.) Stress, worry and illness exacerbated my depression to the point that I couldn't imagine myself ever feeling better. Even during the initial surgeries and radiation I always felt I had at least a small chance of cure. But my mood sunk so low I couldn't see any better future. Thankfully, I realized help was available if only I would ask. Our family doctor prescribed medication that has helped stabilize my depression. Now during the tough times I am much more successful at coping in a positive way.

My family and I have been “blessed” with a very active sense of humor. As Proverbs 17:22 says, “A cheerful heart is a good medicine, but a downcast spirit dries up the bones”. I've found it can be helpful to see glimpses of the funny side in even the most serious of situations, like cancer...especially cancer. I have been known to tell others that I am a proud member of “the cut-throat club”. I can't say that the initiation was much fun, but it's an elite group and I'm in it!

I know I have been at least partly responsible for passing my sometimes offbeat look at life on to my kids. Years ago my young children were asked many times why I looked different. No child likes THAT fact pointed out. It's bad enough to have normal looking parents! Twenty years ago the radiation oncologists did not make patient masks to mark the areas for treatment. The lines were made with a black marker directly on the

patient's face, neck, and chest. I truly looked like a roadmap to who knows where. My son's response to his friend's inquiry about my appearance was, “Oh, you know how my mom is. She just went crazy with the magic marker!” The funny part is that his friend DID know me very well—and was satisfied with that answer!

I know this offbeat look at life has continued into their young adulthood. When my husband was diagnosed with prostate cancer two years ago I asked my daughter how she felt about dealing with cancer again. She laughed and said, “What's the big deal? Don't everyone's parents get cancer?” Humor helps us cope. Both children have now grown to become fun, caring, young adults. Each also has a serious side and has shared our family's cancer experiences with others, especially by writing, even in college. Who knew that cancer could help you get A's in school! Both also volunteer in cancer related activities, such as assisting with children's support programs and fundraising.

Another change brought on by cancer involved my career. I knew that I did not want to return to the stress of the nursing profession or to the limited opportunities in the medical field available in our small town location. I wanted to do something fun that involved children, teaching, and piano. I have been involved with music since childhood, with many years of study, participation in band through high school (where I met my future husband), solo singing as well as ensembles and choirs, even church organist and pianist. We celebrated my completion of radiation treatments with the purchase of a beautiful piano. And since one of the benefits of my husband's faculty position included free tuition for immediate family, I returned to college majoring in music with an emphasis in piano pedagogy.

We have since moved to Columbus and my studio has grown to the point that I am engaged full time in something I love so much that I have never considered it work. Many of my former students have stayed active in music throughout their college years and into adulthood. Some have even entered the music profession as educators, composers, singers, and instrumental performers. Along the way there have been several students touched by cancer in their family. Just being able to listen and offer support has been something I could give. Probably my most humbling experience came when a parent confided that she chose me as her child's piano teacher because she was losing her own battle with cancer. Along with the gift of exploring music together, she

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asked that I provide her six year old child with a different picture of the disease that would eventually end the mother's life.

The Ohio State University Medical Center and Comprehensive Cancer Center has grown to now include The James Cancer Hospital and Solove Research Center. One of the programs offered for patient and family support is MusicCares. It makes available such things as musicians playing for patients, CDs and tapes for listening, and opportunities to participate in drumming circles. For the past five years, my students and I have conducted a "practice-a-thon" for the James. People pay the students to practice and we, in turn, donate the money to the MusicCares Program. The practicing minutes per student really have increased each year. And we have been able to donate over \$10,000 to the James! I am so proud of them. Something as common as children practicing the piano can enable cancer patients to feel better through experiencing music. My students have also learned that even little people can help in big ways.

Now that my own children are grown, my school related activities of PTA, Band Boosters, tutoring, and attending their sports events are over. I do not miss the 5 A.M.

swim practices or the weeklong trips with the marching band, but they were fun times. I am now able to channel that time and energy into volunteering in various ways at the James Cancer Hospital. I have met the most wonderful people from all over the world by being part of a peer support program for oral, head and neck cancer patients. Something I desperately wanted years ago has become a reality for others. Patient response has been very positive and the program is growing.

I also make time for involvement with Joan's Fund. It is an endowed fund formed three years ago in honor and memory of Joan Bisesi, a young mother who tried so hard but died during her struggle with cancer. The fund's purpose is to increase awareness of oral, head and neck cancer and to raise money for research aimed at ending this horrible disease. My hope is that one day people who hear a diagnosis of oral, head and neck cancer will know only the confidence of cure. I've gained wonderful friends who are not physically with me anymore because of this cancer. And I miss them very much. But in volunteering for the James and Joan's Fund I can change my frustration and anger with cancer into something positive that benefits

others and helps me live as a survivor.

I certainly won't say that my life twenty years after a cancer diagnosis is now all sunshine and flowers. I am challenged daily with the consequences of surgery and radiation—minor difficulties with eating and speaking,—the many infections, hospitalization for IV antibiotics, dry mouth, dental concerns, discomfort including periods of severe pain in my face, ear and shoulder, changes in taste, numbness, lymphedema, fatigue. And I still have times of worry that cancer will come again.

But I have decided to be a victor instead of a victim. Cancer will not own me. Thanks goes to my support team of family and friends, medical caregivers, fellow survivors, and excellent doctors who see me as a person instead of a disease process. With God's gifts of faith, hope, love and constant presence I have somehow found courage; facing the future head on, continuing to learn what it means to be a survivor, trying to help others along the way. It's a wonderful life!

*Sharon Renkes*  
Columbus, Ohio

## SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER (SPOHNC)

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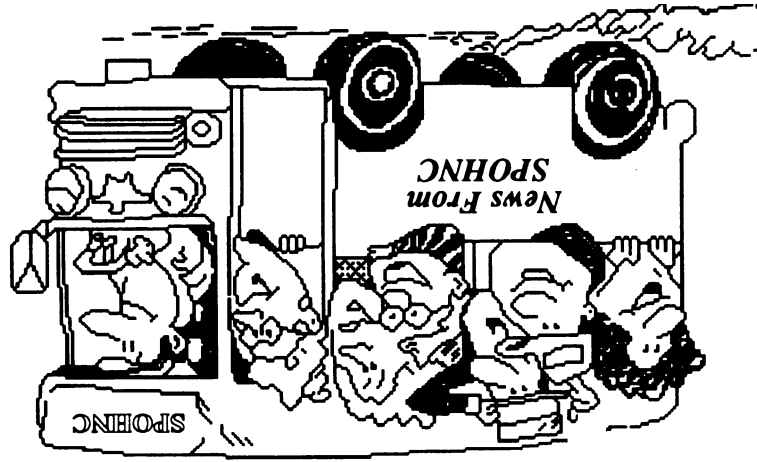
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