

HEADWAY

NEWS ON ADVANCES IN THE PREVENTION, DETECTION, AND TREATMENT OF HEAD AND NECK CANCERS

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How advancing the frontiers of science can improve healthcare

By Jonas T. Johnson, MD

Chair, Department of Otolaryngology, Eye and Ear Institute

All of us have seen personalized medicine discussed in the news. The real question is: What does that mean? Investigators at the University of Pittsburgh and other places are beginning to understand that some cancers that look alike are really quite different. This new understanding has been achieved primarily through evaluation of the actual molecular structure of the DNA that constitutes the tumor. We call this the “genome”. Differences in the genome of tumors which appear to be the same through a microscope can probably be explained based upon differences of the individual patient’s genome and differences in the factors which caused the cancer in the first place. For instance, some cancers are clearly due to tobacco exposure, others are due to exposure to the human papillomavirus (HPV), some are due to exposure to the sun, and, unfortunately, many others are due to exposures that are unknown.

As we become better informed about these differences, there is great opportunity to be able to predict response to therapy. Today, doctors recommend therapies based upon what is likely to work effectively. Unfortunately, these recommendations are usually based upon our understanding of the biology of the tumor, which in turn, is based on a statistical evaluation of what has worked for other patients in the past. These genomic studies have indicated that individuals are very different and the tumors are very different. Accordingly, we are optimistic that the future will allow us to indicate when a certain therapy, such as chemotherapy or radiation therapy, will work, and when it won’t work. We would like to avoid therapy that will not work because almost all of these therapies do cause some harm, and, of course, it makes far more sense to proceed directly to a therapy which has a higher likelihood of being effective.

Today, almost all of the patients treated at the University of Pittsburgh have tumor samples sent to the research laboratories. Additionally, many patients have participated in studies in which medications are administered before surgery to ascertain if there is a biologic effect. We have observed, in a couple of situations, tumors completely resolved based upon these studies. Unfortunately, at this juncture, this has been a chance event, but the improved understanding of tumor biology and the increased availability of various medications work together to allow the future to promise enhanced personalized medicine.



Cancer A Family Affair

By Eva Grayzel



Eva Grayzel (third from the left) with her husband and children Jeremy and Elena

When I returned home from the hospital, my children, seven-year-old Jeremy and five-year-old Elena, could barely look at me. I understood. I could hardly look at myself, even though I kept my sutures covered with scarves and bandages. My children shied away from my touch. How could I blame them? I couldn't bring myself to touch my own wounds.

After my oral cancer treatment, I could barely eat, but I took pleasure in serving my family nourishing food, feeling in some way that it nourished me as well. Elena inspected everything I served carefully. "Mommy, did you take a taste with this fork?" she would ask.

"No, honey, I touched it to my lip to see if it was too hot for you."

"I don't want it," she'd reply, even though we had explained several times that she couldn't "catch" cancer from me.

Often, Elena became angry with me for no reason – she would hit me out of the blue, stick her tongue out, kick my shins. One day, I sat her on my lap and with my radiated, raw vocal chords said, "Elena, tell me why you're angry. What did I do?"

She ran away saying, "Bad mommy."

My husband started putting Elena to bed because she didn't want me to do it anymore. One night I heard her call out, "I want my mommy." Ecstatic, I hurried to her room and said in a hoarse whisper, "It's me, Mom."

"I want my Mommy!" she cried.

I thought she didn't hear me. I leaned closer, rubbed her back as I always had, and repeated, "Honey, it's me. It's Mom."

"But I want my Mommy."

I got it. She wanted her old mommy back. We all did.

I suppose it was good that Elena expressed her feelings. Jeremy was the opposite. He would play by himself with his astronaut action figures and space machines on the living room floor while I rested on the sofa. When I suggested he spend time with friends, he would resist unless they could play at our house. He never wanted to be too far from me. He never asked any questions, even when I reminded him that I would get better soon. I know he was scared, because every time I had a coughing attack, he ran out of the room in fear.

The emotional trauma to my children lasted long after I recovered. Three years after my recovery, Jeremy was with my mother looking for birthday cards. He found a get-well card and said, "Grandma, let's buy this for Mom." She had to remind him that I wasn't sick anymore.

My daughter didn't kiss me for two years. She was intuitive. She knew she could lose me, so she didn't want to commit to one more day of loving me. We learned how to kiss again with a game I made up called "The Smallest Kiss in the World." It was a competition to see which of my children could give me the smallest kiss. Elena took any opportunity to compete with her brother. She angled my face just right and kissed me. I didn't even feel her kiss, yet I told her it was too big, just so I could get another. This game put us on the road to recovery.

My children were greatly affected by watching me struggle with the side effects of oral cancer treatment. Their fear of losing me was deep, real, and bottled. The pain my disease caused my children hurt me more than my disease itself. This was my illness – keep my children out of it!

But it doesn't work that way. Cancer is a family affair.

Stage IV oral cancer survivor Eva Grayzel is a motivational speaker, master storyteller, and author. A champion for early detection, Eva founded SixStepScreening.org, six steps to a thorough oral cancer screening. On the website, you can watch the music video for her "Oral Cancer Save-A-Life Rap." She is the author of two books for children who care about someone with cancer: Mr. C Plays

Hide & Seek and Mr. C the Globetrotter, available in hard copy at Talk4Hope.com and in animated format in the iTunes store. Learn more about Eva at EvaGrayzel.com.

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Healthcare in the Himalayas

By Jonas T. Johnson, MD
Chair, Department of Otolaryngology,
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I recently had an opportunity to help care for people living high in the Himalayas in the country of Nepal on a medical trek organized by Himalayan HealthCare. After landing in Katmandu, we loaded up in a series of Range Rovers. Our team was dropped off at a site over 9,000 feet in altitude after a 6-hour ride. Thereafter, our team of five physicians, three resident physicians, and 11 staff loaded up for a 12-day trek into the mountains. It was necessary to carry not only tents and sleeping bags, but all of our food, cooking utensils, medical supplies and medicine with us. This required hiring over 60 porters (shirpas) who went along with us.

The first village required crossing a peak of 14,000 feet and descending into a deep valley. The trek took two days to reach the village. Approximately 2,800 people lived in the vicinity existing in an entirely agrarian village of Sertung with no electricity and no running water.

We set up shop in a very small school building which allowed us to have a pharmacy in one room and each of the doctors were able to see patients in other rooms. Over the course of the next 2½ days, we saw over 400 patients.

We then packed up our equipment and trekked another two days into the village of



Dr. Jonas Johnson treats a patient in Nepal

Lapa. The tents were set up, the school-house was outfitted, and we began another two days of patient care. Patients requiring special procedures or surgery needed referral to Katmandu. Unfortunately, referral required a 2-day trek and a 1-day bus ride. Accordingly, this was not something available to everyone.

An important part of this medical trek was the fact that we were accompanied by 10 Nepali healthcare providers. These individuals were with us all day long. Every morning began with a lecture provided by one of the visiting doctors. Topics included care for hypertension, chronic lung disease, epistaxis, and ear infection. Thereafter, the Nepali healthcare providers helped us translate and participated in diagnosis and treatment. At the end of this trek, each of these healthcare providers was presented with a certificate documenting his educational proficiency.

Himalayan HealthCare is a non-profit organization founded in 1992. It is committed to improving the life of the rural Nepali people. Every effort was made to leave behind the expertise to sustain these healthcare activities. You can contact Himalayan HealthCare at P.O. Box 737, Planetarium Station, New York, NY 10024; www.himalayan-healthcare.org.

The healing plate

By Leslie Bonci, MPH, RD, CSSD, RDN
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We all know we need to eat to survive, but how about to thrive? Food is more than sustenance, it provides the substance for our cells, bones, organs and brain. I love the idea of eating to nourish, flourish and nurture the body, but underlying all is palatability. We eat with our eyes, as well as our nose and mouth, and the look, temperature and texture are as important as the flavor.

So how do we bring the flavor, fun and flexibility to our meals? Here are my recommendations:

1. Don't be bound by food rules. Who said you can only eat breakfast from 7-10 am in the morning? If you feel like having eggs for dinner, by all means do so.

2. Eat according to your hunger and stop when you are full. On a scale of 1 to 5 where 1 is starving and 5 is stuffed, the goal is to stop eating when you are at a 3. You could eat more, but you are comfortably satisfied.
3. Try to evenly distribute eating over the day. The body is most happy when we try to have about the same amount of food every time we eat. No need for 5-6 small meals a day if you don't want to, three is absolutely fine, but ideally each meal should be:
 - 1/3 protein (chicken, fish, meat, eggs, Greek yogurt, cottage cheese, tofu);
 - 1/3 grains/starchy vegetables (pasta, bread, cereal, rice, potatoes, quinoa, tortillas);
 - 1/3 fruits and vegetables in whatever form you find that you tolerate (with the exception of onion rings).

This will add the color as well as be eye thrilling and gut filling. Here are some colorful tasty examples:

- a stir fry with shrimp and vegetables over rice
- a spinach, mushroom omelet topped with bruschetta sauce and served with a small potato
- a rice bowl with rice, greens, shredded chicken, edamame and pineapple with an Asian sesame ginger dressing
- vanilla Greek yogurt with a little honey, slivered almonds, berries and Bran Buds for fiber
- as it gets warmer, how about a chilled gazpacho with added avocado and served with a bean salad
- halibut or mahi with honey/mustard dressing, a sweet potato and grilled vegetables

4. Summer brings heat and that means you need to drink enough. As I always say, if you're drippin, you better be sippin!
 - create a hydration station in your refrigerator with a clear plastic jug filled with water that is flavored with: ginger, mint and lemon; sliced strawberries and mint; sliced oranges, lemons and limes
 - how about a watermelon smoothie? Freeze chunks of watermelon and strawberries. Take 1/2 cup of each with a splash of orange juice, blend and serve

- chill your tea and try some herbal or decaf types. Pomegranate green tea is delicious and such a pretty color and can be more refreshing than water
5. Be snack savvy. I think it is important for snacks to count and by that, I mean that snacks should be mini meals. You need some protein as well as fruit/vegetables and/or a grain for snacks:
 - hummus and whole grain crackers
 - almond butter on a banana
 - a smoothie with 4 ounces of Greek yogurt, 4 ounces of milk, 1/2 cup frozen fruit
 - a 6 ounce container of plain Greek yogurt mixed with taco seasoning, or another dressing mix and served with vegetables
 - a small bowl of cereal – pick one with fiber and top with yogurt or skim milk
 6. Spice it up – bland food is not appealing. You can improve the flavor of food with a little shake of this or dash of that.
 - sweet tastes: cinnamon, ginger, cloves
 - savory: cumin, garlic powder, basil, oregano
 - spicy: chili powder, cayenne, pepper
 7. Most importantly, make meals a chance to relax and enjoy. Sit, slow down, and make eating an event, not a chore. A nourished body is a happy body.

Bon Appetit!

Exercise and cancer recovery

By Fred S. Como, BS, CPT, CWLS

Cancer is the second leading cause of death in the U.S. and rapidly rising. This is greatly due to the role obesity, inactivity and poor nutrition plays in our body chemistry. Our lifestyle choices are either leading us to health risks, or towards optimal wellness.

For many cancer patients, making it through treatments and getting rid of the cancer is their first and only priority. Second is making sure cancer doesn't return. Abundant research exists providing evidence that exercise and eating right can help prevent cancer growth and recurrence. In separate clinical studies, results have shown even those who begin an exercise and nutrition program post treatment live

longer and have lower recurrence rates. Regardless of your cancer, the positive physiological effects of exercise are the same.

Many benefits of an active and fit lifestyle with the cancer patient/survivor are actually the same for any individual, in that lower fat weight means less health risks. Exercise improves mood, cognitive thinking, self-image, energy levels and sleep quality; increases strength and endurance as well as bone density; decreases anxiety, depression and nausea; and improves circulation. Research has indicated as well, that exercise reduces the cellular risks associated with cancer and helps improve the quality of life for patients and survivors. One of the greater benefits, I feel, in staying active and being more fit means depending less on others as I age.

It is dependent on your fitness levels and tolerance, but in developing an exercise program, the American Cancer Society recommends 30 to 60 minutes of moderate to vigorous exercise five days per week. Programming should include resistance, cardio, core, balance and flexibility training. Working with a qualified and certified trainer will help in establishing a program specific to your abilities and needs. Resistance training (weight training or use of resistance bands and tubes) is highly recommended since cancer patients lose muscle mass and increase fat during treatments. Incorporate the core and balance training to save time. Flexibility and some form of cardio can be done every day. Consider:

- **Cardiovascular training:** treadmill, walking outside, stationary cycle, rowers, low impact or step aerobics, dance, Tai Chi, Yoga, water aerobics, etc.
- **Intensity:** 50% to 70% of your maximum heart rate. (Take 220 and subtract age. Multiply this number by .5 and .7. This will provide the range.)
- **Duration:** Start slow at 5 minutes and build tolerance. Goal may be 30 minutes or more.
- **Resistance training:** 1-3 sets of 10 to 15 repetitions, 2-3 days per week. Be sure the last 2-3 repetitions are challenging.

Because you can never out-train a poor diet, cancer patients/survivors must also consider improvements in nutrition for positive changes in body composition and building a successful wellness program.

Considerations should be:

- whole grain breads and cereal (non GMO)
- drink 100% fruit or vegetable juices (home made if possible)
- drink eight 8-ounce glasses of water
- eat more fruits and vegetables (non GMO and organic – buy local)
- include salad with meals
- limit or avoid sugars, refined sugars, high fructose corn syrup, alcohol, fried or deep fried foods, processed, canned and fast foods
- pick lean meats and fish over processed meats
- include quality nutritional supplements rich in phytonutrients, and antioxidants. Check with your oncologist to see if you should not supplement with additional iron
- for daily protein intake, divide your body weight by 2. This will give you the amount in grams. (e.g. 200 lb. divided by 2 = 100 grams or 3.5 ounces.)
Having a little more may be better for recovery post treatment or surgery

Recovery, like any lifestyle change is most successful with proper planning. Train like an athlete and be a champion!



Fred Como B.S., owner of OneSource Wellness Coaching, is a certified Personal Trainer and Weight Loss Specialist through the National Academy of Sports Medicine. He can be reached at CoachFred@

OneSourceWellnessCoaching.com or www.OneSourceWellnessCoaching.com

Affects of chemotherapy and radiation on hearing and balance

*By Ryan S. Marovich, PA-C, MPAS
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Chemotherapy and radiation are often used as adjunct therapy to minimally invasive and even radical surgery. While these treatments offer increased patient survival, they can affect other structures in close proximity, such as the ear. The lateral temporal bone is an area of the skull base

that contains the ear canal, middle ear, and inner ear structures. Although the temporal bone is not often directly affected by malignant cancer, head and neck cancer treatments can affect the function of the structures in this area.

Radiation therapy causes an inflammatory response in blood vessels, which leads to cellular injury and necrosis, or death of the targeted tissues. Although the involvement of targeted radiotherapy has reduced the “spill over” of radiation to adjacent structures, the lateral skull base still may receive a fair amount of unwanted radiation. Ear related complaints can be expected to occur in 50-60% of individuals undergoing radiation therapy for head and neck cancer and may include chronic infection, hearing loss, and balance complaints (rare). Osteoradionecrosis (ORN) of the temporal bone is a condition that occurs when radiation causes injury to the bone itself. The presentation may vary from one to several years after treatment and is often characterized by a chronic outer ear canal infection, which may present as persistent drainage or pain. The poor ability of bone to heal in this area necessitates long-term care and management. This may include regular ear canal cleaning and the use of topical, oral, and less often intravenous antibiotics. Surgical intervention may be necessary depending upon the extent of damage, although far less often.

Hearing loss can also occur as a side effect to radiation therapy. The incidence is higher when radiation is directed specifically at the temporal bone, but can also occur when other adjacent areas are targeted in head and neck cancer treatment. Nerve related hearing loss occurs when the cochlea (inner ear hearing organ) receives damaging radiation, or if the blood supply to the inner ear becomes damaged. Conductive hearing loss from radiation may occur when serous fluid accumulates in the middle ear (behind the ear drum). Treatment may include oral and nasal decongestants, steroids or even draining of the fluid via a ventilation tube. An alternative treatment to overcome the acquired hearing loss could be the use of a hearing aid, thus avoiding the potential complications of a tube (i.e., infection, persistent perforation). The inner ear balance system may also be affected by radiation therapy, leading to intermittent

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Inspire therapy: a promising new treatment for sleep apnea

By Ryan J. Soose, MD

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Obstructive sleep apnea (OSA) is a very common condition affecting approximately 12-18 million people in the U.S. The problem is characterized by a repetitive narrowing and collapse of the tissues of the throat during sleep. By disrupting sleep, OSA can have detrimental effects on quality of life and neurocognitive function including daytime sleepiness, irritability and mood disturbances, focus and memory problems, as well as an increased risk of motor vehicle accidents. Patients with OSA in the moderate-severe range, particularly with drops in the oxygen levels at night, are also at increased risk for high blood pressure, heart disease, and stroke.

Some patients with a history of head and neck cancer may even be more at risk for OSA either due to the upper airway tumor itself or to the medical or surgical therapy used to treat it. In addition to head and neck cancer contributing to sleep apnea, it now appears that untreated sleep apnea also contributes to cancer mortality risk. A recent study¹ that tracked more than 1,500 patients over a 22-year period provides evidence that patients with untreated severe sleep apnea were approximately five times more likely to die of cancer than those without sleep apnea – even after controlling for other risk factors such as age, smoking, and body weight. This supports findings of previous basic science studies in which cancer cells subjected to low oxygen levels show increased resistance

to treatment and increased malignant progression.

The most commonly used first-line treatment option for OSA is continuous positive airway pressure (CPAP). CPAP therapy involves wearing a mask connected to a machine that delivers air pressure with each breath to keep the airway open during sleep. CPAP has the most data on improving daytime alertness, quality of life measures, and health risks. Nevertheless, approximately 50% of those patients who are prescribed CPAP therapy are unable to tolerate it, often due to side effects or discomfort from the equipment itself. New solutions are needed for these patients.

In 2014, the FDA approved a new OSA treatment option known as Inspire upper airway stimulation therapy. Inspire therapy consists of an implantable nerve stimulator or pacemaker-like device that is placed under the skin of the right upper chest. The device is then connected through the tissues of the neck to the main nerve of the throat muscles. The device is turned on at bedtime by the patient with a remote control. During sleep, the system delivers gentle stimulation to the nerve of the throat muscles in sync with each breath, thus enlarging and stabilizing the upper airway and improving airflow.

A large prospective multicenter trial studying the effect of Inspire therapy was published in early 2014.² In the group of patients treated with Inspire therapy, clinically significant improvements in sleep apnea severity, daytime alertness, quality of life, and snoring were observed and even sustained at the one-year mark. Two-thirds of the patients in the study had excellent control of their sleep apnea although many more reported improvement in their sleep-related symptoms and subsequently good patient satisfaction with the therapy.

Based on the current data, patients who would most likely benefit from Inspire therapy are those with moderate-severe OSA, who are not significantly obese, and who are intolerant or struggling to achieve benefit with CPAP. Interested candidates, who would like more information on this or any other treatment or to see if Inspire therapy is an option for them, can contact the UPMC Division of Sleep Surgery in the Department of Otolaryngology at 412-232-3687 (Mercy) or 412-374-1260 (Monroeville).

1. Nieto FJ, Peppard PE, Young T, et al. Sleep-disordered breathing and cancer mortality: results from the

Wisconsin Sleep Cohort Study. *Am J Respir Crit Care Med* 2012; 186: 190-194.

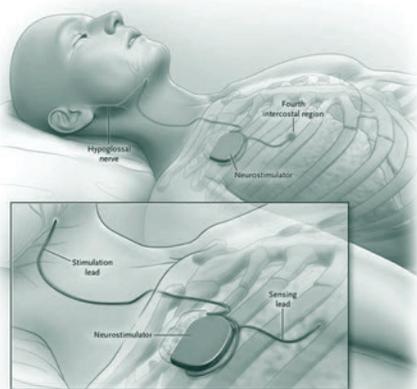
2. Strollo PJ, Soose RJ, Maurer JT, et al. Upper-airway stimulation for obstructive sleep apnea. *New Engl J Med* 2014; 370: 139-49.

Affects of chemotherapy and radiation on hearing and balance

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vertigo or balance complaints, although the incidence of this is generally low.

Chemotherapy has been used alone, or in conjunction with radiation therapy, for the treatment of certain head and neck cancers with a great deal of success. Certain anti-neoplastic (chemotherapy) agents however, can have their own less than desirable side effects on the hearing and balance system (ototoxicity). The most well-known ototoxic agent in this medication class is Cisplatin. Hearing loss caused by Cisplatin is highly variable and dependant upon factors such as patient age, dosage administered, genetic susceptibility, and other environmental factors (i.e., history of noise exposure). Damage to the inner ear is thought to occur from the development of reactive oxygen species, which are harmful to the inner ear. When inner ear structures are injured, permanent high frequency hearing loss and tinnitus may ensue. Prevention of ototoxicity begins by assuring the patient is well hydrated and that kidney function remains adequate for proper clearance of the drug in the urinary system. Hearing can be monitored during treatment for high-risk patients with standard audiometric testing, or with more specialized auditory function studies that may detect hair cell damage earlier on. If necessary, treatment regimens can then be tailored to prevent further hearing or balance loss when appropriate. With the advent of more effective and less invasive treatments for head and neck cancers has become an increasing awareness of, and decrease in incidence of, treatment related side effects.



The Inspire upper airway stimulator

For additional topics on the prevention, detection and treatment of cancer, including head and neck cancer, visit http://www.upmc.cancercenters.com/portal_headneck/publications.cfm for archived issues of *Headway*.



Swallowing Disorders Center

The UPMC Swallowing Disorders Center is dedicated in helping patients with swallowing problems as they undergo treatment for head and neck cancer. Early intervention with swallowing exercises has been linked to better quality of life outcomes. It is highly recommended that patients be seen by the swallowing team to begin a therapy program as soon as the plan for treatment has been identified.

The process begins with a swallowing evaluation to assess baseline swallowing function and to identify if posture changes, swallowing strategies, and/or diet modification will help the patient swallow better. While some patients require a feeding tube during the course of treatment, the ultimate goal is to return to eating and drinking as soon as possible. We provide assistance during the transition from a modified diet or tube feedings back to a regular diet. When returning to a regular diet is not possible, we help to develop an individualized plan to take certain foods or liquids safely.

We recently completed a study in which weekly questionnaires were given to eleven patients as they underwent chemo-radiation therapy to help us better understand what patients experience during the phases of treatment. This type of information is helping us tailor our therapy approaches to achieve better outcomes. For most, increased difficulty with swallowing occurs toward the end of treatment and may even last a few weeks after the completion of treatment. Once patients are feeling better, the goal is to re-establish the exercise program and begin aggressive intervention so patients can return to an oral diet safely. The team is also participating in a multi-center study involving a special device to exercise the tongue. The device measures baseline tongue pressures so patients can improve strength with practice and meet specific target goals. Grip strength assessments are also being used in the center to determine if there is a relationship between weakness and dysphagia (difficulty swallowing).

The UPMC Swallowing Disorders Center has two locations:

- UPMC Eye & Ear Institute (Oakland) 412-647-6461
- UPMC Shadyside 412-621-0123

Clinical trials

For more information about head and neck clinical trials, contact Amy at 412-383-2083 or Denise at 412-383-2085.

Contact information

American Cancer Society.....	1-800-227-2345
Assistance with Coping.....	412-623-5888
Cancer Caring Center.....	412-622-1212
Cancer Information and Referral Services.....	412-647-2811
Clinical Trials.....	412-383-2084
Eye & Ear Foundation.....	412-383-8756
Family Care Giver Education and Support.....	412-623-2867
Gilda's Club of Western PA.....	412-338-1919
Gumberg Family Library.....	412-623-4733
Head and Neck Cancer Support Groups	
North Pittsburgh (Wexford/Franklin Park).....	412-864-2532
South Pittsburgh (Bethel Park/Upper St. Clair).....	412-622-1212
Hopwood Library at UPMC Shadyside.....	412-623-2620
Hyperbaric Oxygen Treatment.....	412-647-7480
Pain and Supportive Care.....	412-692-4724
Project of Love (comfort pillows).....	724-266-8007
Prostate Cancer Support Group.....	412-647-1062
Satchels of Caring Foundation.....	412-841-1289
Swallowing Disorders Center	
UPMC Eye & Ear Institute (Oakland).....	412-647-6461
UPMC Shadyside.....	412-621-0123
UPMC Division of Sleep Surgery	
Mercy.....	412-232-3687
Monroeville.....	412-374-1260

American Cancer Society website.....	www.cancer.org
Head and Neck Cancer Program website.....	www.upmccancercenters.com/headneck
Hillman Cancer Institute website.....	www.upci.upmc.edu

Head and Neck Cancer Program website

Looking for more information about patient services, current research, clinical trials, news and events and other valuable information pertaining to head and neck cancers? Check out the website for the Head and Neck Cancer Program of UPMC Cancer Centers at www.upmccancercenters.com/headneck.

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