

HEADWAY

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

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Eye and Ear Institute kicks off first survivorship clinic

By *Jonas T. Johnson, MD*

Chair, Department of Otolaryngology, Eye and Ear Institute

The Commission on Cancer as well as the Institute of Medicine have encouraged doctors treating patients for cancer to provide more comprehensive information about their treatment to both patients as well as their doctor. This should include a printed plan for continuing survivorship.

Survivorship has been described as the period in a person's life after they have been diagnosed with cancer. The first stage of survivorship, of course, is treatment. After treatment, however, life does go on. In terms of patients treated for cancer of the head and neck, the first period is recovery from the treatment. Surgery causes pain, swelling, and some deformity. Chemotherapy and irradiation therapy cause other, sometimes severe, side effects. The most acute effect is a painful burn. This is often associated with disturbance in taste and a change in the saliva because the salivary glands are injured.

Following recovery from the acute side effects, almost every patient finds that their body has been changed forever. Common problems include a change in the saliva, excessive thick mucus, loss of taste and eventually loss of teeth. Other problems can develop such as stiffness in the neck and shoulders and, of course, difficulty swallowing. Less common, but very important, challenges include progressive loss of hearing (the causes vary) and the onset of anxiety and depression. These challenges can affect quality of life and in some situations lead to frustration and depression.

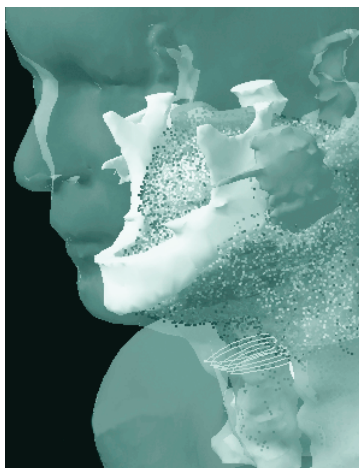
The UPMC Survivorship Clinic has evolved from the Swallowing Center which has been available to patients for over two decades. The Survivorship Clinic is a collaboration between nursing, doctors, swallowing therapists, dental medicine, and other healthcare providers. Patients are comprehensively surveyed regarding their needs in an effort to identify potential areas with which we can help. The clinic includes routine checkup and surveillance for tumors. It also includes the opportunity to have a specialized evaluation of swallowing if swallowing difficulties have developed. The next step is to be evaluated by Dr. Susan Calderbank, a dentist, who has special interest and expertise not only in caring for existing teeth, but for treating dry mouth, oral sensitivity, and difficulties in opening the mouth. Consultation with a dietician may be appropriate and helpful for some people who have hypersensitivity to certain foods.

We are offering a screening for hearing loss. Sometimes people develop some hearing loss after surgery or radiation. A physical therapist will be available to help people who need assistance in maintaining motion and strength in their jaw, neck, and shoulders. We are linked to professionals in behavioral health to facilitate referral.

Our efforts in the Survivorship Clinic are to identify patients who need help and then to provide access to resources which may improve quality of life. All patients who have been treated for cancer of the head and neck are invited to be evaluated. To schedule an appointment, call 412-647-2100 and identify yourself as a head and neck cancer survivor. Access to these facilities is counted as a single doctor's visit and you will not be required to deal with multiple payments or copayments.



Multidisciplinary survivorship team (l to r): Jatta Bluefort, Marci Nilsen, PhD, Tami Wasserman, Lori Zitelli, Susan Calderbank, DDS, Jonas Johnson and Susan George



It had to be a miracle

By Diana Bartakovich
Cancer Survivor

Almost three years ago, after noticing unexplained bruising, I was diagnosed with MDS (Myelodysplastic syndromes) considered a type of cancer of the bone marrow, complicated by “moderate” fibrosis (scar tissue). I had two blood cell types affected (red and platelets). Unfortunately MDS is not a very studied form of cancer. The only published study I was able to find of patients with similar diagnosis cited an 18% chance of a cure, with a 45% chance of reoccurrence! My diagnosis was confirmed by two additional specialists. A bone marrow specialist from Johns Hopkins actually compared my condition to “winning the lottery backwards...twice”! Also, when confronted, she sadly confirmed my suspicion that the recommended treatment was nothing more than (my words) “a shot in the dark.” They all agreed that 1) I was a very sick woman, and 2) my only hope for a cure was a bone marrow transplant (which involved a high dose of chemotherapy, followed by years, if not a lifetime of medications to keep the side effects under control...if I survived). Nothing about this treatment gave me any hope for eventual health. However, they explained that if I chose not to get the transplant, I had a 30% chance of developing MDS, a usually fatal type of leukemia, or a 100% chance that my bone marrow would eventually shut down from being overworked. I asked how long I would be able to keep things under control without the transplant. Possibly eighteen months! When I asked each of these specialists if changing my diet, detoxing, etc. could help, they quickly assured me that it was absolutely impossible to cure my disease without the transplant...and I absolutely could not accept that!

I have long believed that God gave us amazing bodies, capable of amazing healing, and always, always believed in miracles! But people would gently remind me that “often God uses doctors for our miracles,” so I started looking into alternative treatments. I quickly became frustrated and overwhelmed with all of the information, but could find

absolutely nothing specific to my diagnosis. I cried out to God over and over again to please give me direction. I attended a healing mass, had prayerful hands laid on me, and so many prayers on my behalf...but wondered if it really would be God’s will to heal me!

Meanwhile, I tried my best to do everything healthy for my body that was within my reach. With the support and help of my family and friends, I did a whole body detox, changed my diet to an all organic, no sugar, no grain, nutrient dense diet, juiced daily, started making my own kombucha, raw milk kfir and bone broth. It was all time consuming, but with my weekly lab results showing my disease progressing, I still desperately felt I needed to do more!

I was trying to stay strong, but during my alone moments, I continually cried out to God. “Please tell me what you want me to do!” We were all praying and hoping for a miracle...but then the fear of my daughters turning away from God if I did not survive became more terrifying than the disease. I took these new fears to God over and over again, each and every day, and kept pleading my case. It just wasn’t about me living or dying anymore, it was also a battle for my daughters’ faith!

Then one day, I had a phone conversation with one of my sisters, and although we agreed that God was going to heal me, I again shared my fear that I had no idea what He wanted me to do to heal! I realized I was just going around and around, getting stuck in the ‘what He wanted me to do,’ but I couldn’t seem to get past it! She encouraged me to just keep praying on it and after hanging up, I sat for a moment and asked Him again. As I was turning out the light to leave the room, I felt/heard in my heart/soul “Seek me first.” That was it! I knew I got my answer! Praise God!

From that moment on, I decided to no longer stress and worry about a treatment, but to wholly focus my searching to God’s word...specifically His word about healing. I had previously received a book, from an unlikely source, titled *Becoming a Man of Unwavering Faith* by John Osteen. I dug into it and it led me to specific healing verses in my bible. It became such a hunger, that I only wanted

to keep digging deeper and deeper. My faith was growing! I now knew that it surely was God’s will to heal! I dug in and stood firm on His promises. I began praising and thanking God for the healing He had promised me and asked everyone who was praying for me to do the same. I continually repeated Psalm 118:17 “I shall not die, but live and declare the works of the Lord,” along with so many other verses that promised me healing. I knew I only had to wait until it was manifested in my physical body. I felt like the weight of the world was lifted off my shoulders. I was a happier me!

Still, my lab results showed no improvement. At the worst of my illness, as I continued to turn down the transplant, all my blood counts dropped to alarmingly low levels. For over six months, I was requiring a blood transfusion every three weeks...a week longer than recommended by what my blood counts indicated, but I felt so much better than what was expected. I was able to continue working full time, only taking time off for appointments and transfusions. I was convinced that healing was just a matter of time, and ignored the sad expression on my doctor’s face every time he tried to address the idea of moving forward with the transplant.

Although I was believing God for my healing, there were times that fear would creep back in and doubts would try to surface, especially after my weekly appointments continued to show progression. I so wanted to see something that confirmed what I knew in my heart.

Through faith, I started to realize that although I was believing God for healing, I wasn’t totally trusting in His perfect ways and timing. I made a declaration to have a spirit of trust, never a spirit of fear. No matter what my lab results showed, or what my doctor believed, I would not fear. I rebuked all thoughts that did not agree with God’s promise for my healing. I won’t lie. It was a battle! But I knew that God already won this battle for me! It was a done deal. I was not only a happier me, I was down right joyful!

Amazingly, it has been two years since my last transfusion! My bone marrow just started making more and more healthy

blood cells and my disease has steadily reversed! My last lab results confirmed that my blood counts are (PRAISE GOD!) normal! My doctor just shakes his head and tells me that this is medically impossible! He asked me what I did, then said it had to be a miracle.

I will always be incredibly thankful for all those who encouraged and supported my decision not to go through with the transplant and helped me in my conviction to challenge conventional medical “wisdom” and strive for true health! But most of all, I thank God, our perfect healer, for adding His “super” to my “natural”! With God, nothing is impossible!

Four ways exercise can benefit you

By Fred S. Como, BS CPT, CWLS

I've often talked about the many benefits of exercise and an active lifestyle. Some of those being increased energy, improved self image, improved mobility and job performance and many others. What very few explore is the many positive effects exercise and activity have on preventing cancer. Even those in remission or in recovery can benefit from a more active lifestyle. The Centers for Disease Control and Prevention (CDC) recommend that adults “engage in moderate-intensity physical activity for at least 30 minutes on five or more days of the week,” or “engage in vigorous-intensity physical activity for at least 20 minutes on three or more days of the week.”

So how can exercise be of benefit to you? Here are some of the ways exercise can help prevent cancer in the future and aid in your recovery from being treated.

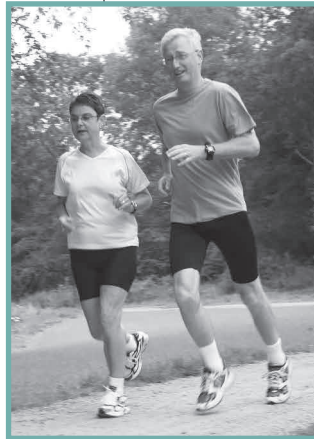
The most well known benefit is to reduce obesity. The National Cancer Institute reports that obesity is related to many forms of cancer, including esophageal, pancreatic, colon and rectal, breast, endometrial, kidney, thyroid and gallbladder.

How does this happen? Fat cells produce excess amounts of estrogen, as well as insulin and insulin-like growth factor-1

which has been shown to promote growth of certain cancer cells. Fat cells also have an effect on other hormones which leads to inflammation in the body, promotion of cancer cell growth and proliferation and a reduction in immune system function.

Exercise, conversely, helps produce hormones to fight inflammation, improve immune system functions, reduce fat (particularly the visceral adipose tissue closer to internal organs and more responsive to hormone production) as well as control the excess hormone levels negatively affecting your health.

Exercise plays a key role in hormone production. For example, increased cardiovascular exercise can help in the production and release of serotonin by increasing the production of tryptophan. Ultimately, your mood can be enhanced and depression reduced.



Cortisol, known as the stress hormone, can be reduced in the body through exercise. High levels can wreck havoc on the body by reducing muscle tone and bone density, slowing healing, impairing the immune system, disrupting hormone production, impairing digestion,

metabolism and mental function and interfering with the endocrine function.

To truly benefit the body, healthy hormone levels are key. Exercise is vital to maintaining healthy, functional hormone production.

Bone density is always a concern for cancer patients and those in recovery. Chemotherapy and radiation both have profound effects on the body and bone health is a concern for all patients. As with all aspects of exercise, a well balanced diet is all important and can not be stressed enough. Resistance training is the major exercise we look to for good strong bones. However, cancer patients must take cautionary steps in how intense their training should be. Heavy lifting may need to be avoided in order to prevent injury. Everybody has a different story and every approach is going to be different.

Energy is something everyone wants more of. There are many causes related to low energy levels people suffer. Cancer treatment is going to be hard on the body and having less energy can be experienced by almost every patient. Approaching treatment along with a regular exercise program can help curb energy loss. This is actually one of my favorite things to talk about with clients.

First off, more mitochondria form in the muscle. These cells produce energy for the body. So again, resistance training plays a key role (as does a quality nutrition plan). The mitochondrial cells convert glucose, fat and oxygen to produce more energy. So you can see the benefits right off.

Exercise creates tiny blood vessels which in turn help deliver more oxygen to the body. Along with cardiovascular exercise, the body becomes more efficient in delivering higher volumes of oxygen. This not only promotes better energy levels, but aids in healing the body.

As with other hormonal improvements, exercise increases the release of endorphins to the body helping you feel good, improve mood and also increase energy levels and feelings of alertness.

Your sleep will improve. Regular exercise will help you enter into a deeper level of sleep and help you get more time in this deeper level. Thus, your energy levels are going to be higher upon waking.

An overwhelming body of evidence proves the benefits of exercise on our health. By reducing obesity, improving hormone levels, maintaining muscle tone and bone density and improving energy levels, your road to recovery and towards better health can be achieved.

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Importance of having a swallowing evaluation prior to chemoradiotherapy

By *Lindsay Savinda, M.S. CCC-SLP*
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Dysphagia, also known as difficulty swallowing, is defined by various different symptoms such as coughing/aspiration (i.e., liquid in the airway), inability to control food or saliva, and food sticking. Swallowing problems are common in patients with head and neck cancer. These problems are often present at the time of diagnosis, during chemoradiotherapy (CRT), and post treatment as a result of treatment related toxicity (i.e. pain with swallowing, thick saliva, mucous, altered taste, swelling, and stiffness). Dysphagia can place patients at risk for aspiration pneumonia (i.e., life threatening condition), malnutrition, and dehydration. This is why early identification is important for the management of swallowing problems throughout the course of treatment.

A swallowing evaluation is necessary to identify specific problems and to improve safety of swallowing during and post treatment. Early identification begins with baseline testing prior to CRT, by a speech-language pathologist and/or multidisciplinary swallowing team. This allows for proper implementation of strategies or diet modification enabling patients to continue eating throughout the course of treatment. Eating and participating in swallowing exercises during the course of treatment is encouraged to help maintain function and strength of the muscles in the mouth or throat.

The UPMC Swallowing Disorders Center team evaluates and treats patients with these problems. A review of 116 patients with head and neck cancer was completed to identify who aspirated (food and/or liquid going into the airway) on the initial swallowing evaluation before the start of CRT. The results showed that patients who reported swallowing problems aspirated 45% of the time, and 94% of these

patients benefitted from some type of intervention (i.e., diet change in texture or swallowing strategies) to reduce aspiration risk. Patients with large tumors (T4) aspirated 50% of the time.

These findings demonstrate the need for having a swallowing evaluation before the start of CRT. The Speech Language Pathologist can help identify what makes swallowing easier and safer. Early intervention and assessment is recommended to determine the most appropriate diet and treatment plan. Assessment is recommended for all patients receiving CRT. Dysphagic patients can be supported during therapy and the incidence of aspiration related complications can be minimized.

Patients can receive this current standard of care by visiting the UPMC Swallowing Disorders Center located in the Eye and Ear Institute in Oakland (412-647-6461) or in the medical building at Shadyside Hospital (412-621-0123).

Personalized cancer care in the genomic era

By *Mark Kubik, MD*
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University of Pittsburgh

The management of head and neck cancer (HNC) is evolving rapidly. Recent advances have included prevention with Human Papilloma Virus (HPV) vaccination, chemoradiation protocols, and surgical innovations in minimally invasive robotic procedures and reconstruction. These have improved the quality of care and reduced the functional & cosmetic impact of treatment. Despite these encouraging changes, studies suggest that no improvement in survival probability for HNC has been seen in recent history.

Historically, cancer treatment is based on variables such as tumor size, anatomic site, and evidence of spread to lymph nodes or distant organs. We know, as mentioned above, that this process is generally effective but often imperfect.

Recent developments in the field of molecular biology have led to a better appreciation of the genetic basis for many diseases. An individual's genetic makeup, or genome, serves as the blueprint for

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



biology and function. Human genetic information is coded in long sequences of nucleic acids (DNA) on 23 chromosomal pairs. In 2016, due to advances in sequencing technology, an entire human genome can be studied comprehensively in a few hours for a reasonable price.

Cancer, most fundamentally, is a genetic disease. Cancers result from cells that accumulate genetic permutations that facilitate uncontrolled growth and replication. Understanding the genetic mechanisms of cancer and other diseases has ushered in the era of personalized medicine in which treatments are individualized on the basis of genetic tests. How can personalized medicine revolutionize cancer care? Characterizing the genetic profile of a tumor may allow the clinician to optimize treatment selection for a patient and also identify patients that will benefit from targeted drugs that block specific biologic pathways driving tumor growth.

Investigators at the University of Pittsburgh were among the first to independently describe the head and neck cancer genome in 2011. We have learned that the one disease that we conventionally describe as squamous cell carcinoma is actually remarkably heterogenous and complex from a genomic perspective. Just as every individual is unique, every cancer is genetically unique and could potentially benefit from a personalized approach to therapy.

Interest in personalized oncology is exploding. Annual spending on targeted therapies in the U.S. now exceeds \$10 billion, outpacing spending on conventional chemotherapies. Several targeted drugs have been approved for use in HNC or are under investigation in

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Personalized cancer care in the genomic era

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clinical trials. Cetuximab was the first targeted therapy in head and neck cancer to gain FDA approval in 2006 followed by pembrolizumab and nivolumab in 2016. These drugs inhibit specific biologic drivers or, in the case of pembrolizumab or nivolumab, modulate the host inflammatory response to the cancer.

In the coming years, genetic characterization of cancers and personalized oncology should revolutionize head and neck cancer care. There will almost certainly be barriers, likely cost related, but these advances should allow us to deliver treatments customized to patients to optimize the possibility of cure and limit treatment related side effects.

When fear takes on a life of its own: fear of cancer recurrence in HNC

By Laura B. Samuelsson, MS
Doctoral Candidate

It's natural to fear cancer – it feels like something alien, frightening, and completely unwelcome and out of our control. But for those who have never been diagnosed with cancer, this fear most likely lurks in the shadowy recesses of the mind, called up and noticed only when the topic of cancer arises, or when a spouse or friend is diagnosed.

For those living with cancer, the fear changes: it is no longer a fear of *getting* cancer in the future, but the fear of facing and dealing with the cancer in the present. These fears are logical and readily understood by patients' treatment teams and families, but it can be hard for these same people to understand the fear of cancer recurrence (FCR) that may be felt by cancer survivors. Survivors have withstood the stress and trauma and loss that

accompany diagnosis, rounds of treatment, innumerable medical visits and hospital stays, the emotional challenges to their sense of identity and appearance, blood draws and biopsies and the anxious waiting for results. For cancer survivors, the fear of cancer is no longer the shadowy villain lurking in the back of the mind. It becomes an actor in their lives, an unwanted guest in their homes.

It is critical that HNC survivors (and all cancer survivors) understand that FCR is common, occurring in anywhere from 20-80% of survivors. Patients have every right to be concerned over their cancer returning. However, they also have every right to request and receive help and support in order to learn ways to cope better with their FCR. For those patients who don't know how to cope with their FCR in healthy ways, the fear of cancer recurrence may lead to poorer quality of life, more impaired functioning, and feelings of intense anxiety, lack of control, and hopelessness.

A majority of HNC survivors report that their FCR is their most distressing post-treatment concern, yet they find that their treatment teams and medical providers do not ask them about their FCR, nor do they offer any help or make referrals to address the FCR. Surveys of oncologists have found that most physicians simply do not know how to identify or discuss FCR with their patients. As a result, FCR is often overlooked or never discussed. This may leave patients feeling like their FCR is unimportant or invalid, or even worse, that they are somehow abnormal or different for being so preoccupied with the possibility of the cancer returning.

It is critical that survivors understand that, as with most human experiences, fear of cancer recurrence exists on a continuum, from normal levels of FCR to severe FCR. It is also critical that survivors understand that there are many different ways to deal with FCR, and that

some of these methods can be downright harmful. Severe FCR may cause some people to use unhealthy coping behaviors, such as increased smoking and drinking, cutting themselves off from socializing with friends and family, avoiding medical checkups and ignoring their physical health, and even refusing beneficial treatments, usually with the thought, "What's the point if my cancer is just going to return?". It is easy to see how FCR can impact quality of life – the fears themselves may cause people to feel anxious and defeated, sometimes so much so that these people do things that make them feel even worse.

If you are a cancer survivor, take the time to answer this one question:

Do you have a fear of the cancer coming back? (check one box)

- I have no fear of recurrence
- I have a little fear, with occasional thoughts, but they don't really bother me
- I am sometimes having fearful thoughts but I can usually manage these
- I get a lot of fears of recurrence and these can really preoccupy my thoughts
- I am fearful all the time that my cancer might return and I struggle with this

(Rogers et al., 2016)

If you selected either of the last two options, you may want to consider bringing up your FCR with your treatment team. Let them know that you are very concerned about your cancer returning, and ask them for resources to help you learn how to address your fears and cope better with your FCR. Many psychologists and psychiatrists are trained in working with survivors to reduce their FCR and help them regain a sense of control over their worry and improved quality of life. You aren't the only survivor who worries about cancer recurrence, so why should you go through this alone?

Reference: Rogers, SN, Cross, B, Talwar, C, Lowe, D, & Humphris, G. (2016). A single-item screening question for fear of recurrence in head and neck cancer. *Eur Arch Otorhinolaryngol* 273:1235-1242.

Head & neck cancer support group

A cancer support group, primarily for head and neck cancer patients, family members, and caregivers is available in the Pittsburgh area. The group meets the first Wednesday of each month at UPMC Cancer Center, Upper St. Clair, 200 Oxford Drive, Suite 500, Bethel Park, Pa. To register, call 412-622-1212.

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 412-864-1728 or Denise at 412-864-3759.

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.....	412-864-1728 or 412-864-3759
Eye & Ear Foundation.....	412-383-8756
Face2Face Healing.....	1-844-323-4325
Family Care Giver Education and Support	412-623-2867
Gumberg Family Library	412-623-4733
Head and Neck Cancer Support Group.....	412-622-1212
Hopwood Library at UPMC Shadyside.....	412-623-2620
Hyperbaric Oxygen Treatment.....	412-647-7480
Our Clubhouse.....	412-338-1919
Pain and Supportive Care	412-692-4724
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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