

HEADWAY

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

Page 1

New therapeutic opportunities on the horizon for cancer victims

Page 2

Katmandu! Wow!

Principles of head and neck cancer reconstruction

Page 3

Cancer – whatta, whatta, whatta...BLESSING!

Page 4

What is dysphagia?

What is stereotactic radiosurgery?

Page 5

The sacred work of caregiving

Page 6

Swallowing Disorders Center

Clinical trials

Contact information

Head and Neck Cancer Program website

New therapeutic opportunities on the horizon for cancer victims

By Jonas T. Johnson, MD

Chair, Department of Otolaryngology, Eye and Ear Institute

Surgery and radiation therapy have been the mainstay of treatment options for patients with squamous cell carcinoma of the mouth and throat. In the past two decades, researchers have demonstrated that the addition of some forms of chemotherapy make irradiation more effective. These observations have resulted in a variety of treatment options which sometimes allow patients to avoid major surgery. For instance, we know now that patients with advanced, but limited, cancer of the larynx can avoid having their voice box removed under some circumstances if they are treated with a combination of chemotherapy and irradiation. Unfortunately, this treatment is toxic and often results in some significant side effects such as loss of saliva, disruption of taste, and difficulty swallowing.

Investigators at the University of Pittsburgh and other major cancer centers across the country have identified new agents which affect tumor growth, but do not have the toxic side effects of conventional chemotherapy. The first of these to be licensed is a drug called Erbitux (cetuximab). This drug was first licensed about seven years ago. Since that time, a multitude of agents, most of which are monoclonal antibodies or tyrosine kinase inhibitors, have been introduced to the medical world as having potential therapeutic value in the treatment of squamous carcinoma.

Concurrent with the understanding of the biology of these agents has been the development of the ability to do testing of the cancer genome. At this point, we are hoping that a more in depth understanding of the interaction between these growth inhibitors and the actual genome will allow for the doctor to actually target a specific cancer to stop it in its tracks without subjecting the patient to many of the conventional side effects associated with chemotherapy.

At the University of Pittsburgh, we have been undertaking a series of biomarker studies in which patients scheduled for surgery to remove a mouth cancer are administered an oral tablet for 2-4 weeks before surgery. We are delighted to report that on two separate occasions the tumor was completely eliminated by the tablet. This gives us great room for optimism, however, we must acknowledge that the ability to completely block the tumor growth in an individual patient is not yet predictable.

We need to invest in continued new science to bring these technologies to the point where they can be reliably counted upon to cure cancer with fewer side effects.



Katmandu! Wow!

By Howard B. McDaniel

Diagnosed with Adenoid Cystic Carcinoma on the base of his tongue in January, 2009, Howard subsequently underwent hemiglossectomy with free-flap reconstruction followed by chemo-enhanced radiation.



I began to understand how smart phones had changed the world when I received an email from a friend trekking in Nepal. He was a German whom I had met on an on-line forum for Adenoid Cystic Carcinoma, the rare cancer I was diagnosed with in 2009. My recent scan showed lung mets and I had sent him an email asking how he had treated his mets. When I received his reply and saw that it was from Katmandu, I began to better understand how interconnected the world had become – and how much these changes were helping people like me. Here I was sitting in my living room in rural north-west Pennsylvania trying to sort out my treatment options when I receive a note from someone trekking in Nepal. Wow! It really made me pause. How fortuitous to live in an age when communication is so global and yet so personal. Living with a rare cancer that most doctors never see has put me on a road of confusing questions and elusive answers. I need all the help I can get and the internet's capacity to connect me to others who have similar issues has been an invaluable asset in understanding my treatment options.

It seems like so long ago, but in the beginning I discovered an on-line site for Adenoid Cystic Carcinoma almost by accident. I was searching to find out everything I could about ACC when I ran across the ACCOI (Adenoid Cystic Carcinoma Organization International) forum site. Here was a site that brought together people with ACC from all over the planet; people who were living with the effects of unfathomable head and neck surgeries, radiation, and the fear of what the next scan might show. Here were people who had insight from their own experiences and knowledge from their own treatments. Here were people connected to surgeons and radiologists across the globe, willing to share information about what treatments they were trying, what treatments caused more harm than good, and what

treatments worked, all essential information when dealing with an orphan disease. What a critical resource to augment what my doctors were

telling me. What a vital source of sometimes actionable information that I could pass along to my doctors.

Then, there was the aloneness of it all, the overwhelming feeling that my wife and I were, in a sense, facing this dreadful disease alone. Yet how quickly we felt the friendship of an on-line community and knew that we were not alone. There were others out there with the same unpredictable and relentless disease, others who understood what we were going through, and were there to help us with knowledge from their experiences. We were suddenly, unexpectedly, members of a community, and for that we will be forever thankful.

It didn't stop there. On another front I was having issues with my g-tube when again by accident I discovered Oley, an online forum for people with feeding tubes. I was astonished. Here was a place, a community, where I could go to ask questions and receive answers from tubers across the globe. Here was a place where I could go to see how others managed issues such as granulated tissue, leaking tubes, excessive intestinal gas, or the merits of canned nutrition versus blended diets. I finally had a place I could go to compare notes on how tubers deal with eating out, hiking, and of course, traveling and getting the miscellaneous liquids and curious eating paraphernalia through airport security. I could ask the big questions or I could post a thought, looking for feedback and insight, and get a variety of answers. Sometimes the answers would be concrete, but at other times, the answers would begin a dialogue that would lead to a better understanding. Moreover, the forum led me to tuber Facebook groups providing me with other pathways to information, camaraderie, or just venting, and to know that at a moment's notice there were others ready to help me whenever I needed it. It made me wonder what people used to do. It made me see how things were improving. It gave me hope.

Knowledge, insight, hope, and friendship at your fingertips...how good to live in the 21st century. Katmandu today. Timbuktu tomorrow.

Principles of head and neck cancer reconstruction

By Mario G. Solari, MD

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Comprehensive care of head and neck cancer patients requires a multidisciplinary team. Among the long list of caregivers who aim to deliver the best possible survival and quality of life outcomes is the reconstructive surgeon. This article will review who can benefit from reconstructive surgery and will describe the fundamental techniques used in modern care.

Most cancer therapies, such as surgery, chemotherapy, and radiation therapy, will have some side-effect that may compromise the cosmetic appearance of the neck, face, or scalp or compromise the function of the complex structures involved in speech and swallowing. This may occur at the time of cancer surgery or months or years later in patients who are cancer-free. Deformities of the head and neck can have a significant effect on self-esteem, ability to socialize, and overall quality of life.

The first step in evaluating a patient who may benefit from reconstructive or restorative surgery is defining the problem and establishing the goals. The major goals of reconstructive surgery involve restoring or improving physical appearance and function of the aerodigestive tract (nose, lips, mouth, jaw, and throat), protecting vital structures like blood vessels and nerves, and enabling critical therapies such as chemo and radiation therapy. The reconstructive surgeon, who may be the ENT surgeon removing the tumor or a plastic surgeon, will design a plan that will meet realistic goals established with the patient with the least invasive surgery possible. There are many patient-specific factors that go into this decision such as medical problems, smoking status, past or future chemo/radiation therapy, and overall functional status. Two different patients with the same cancer resection defect could end up with very different reconstructive plans.

A basic tool used by the reconstructive surgeon is the “reconstructive ladder.” It lists reconstructive procedures from simplest to the most complex. The more complex the problem, the higher one must go on the ladder:

- **Secondary healing**

This involves leaving wounds open to heal on their own. Small defects in skin or the lining (mucosa) of the oral cavity or pharynx can heal fine this way.

- **Primary closure**

This is the simplest closure where the edges of skin or mucosa are pulled together without significant tension and sutured. This leaves no open wounds.

- **Skin grafts**

Sometimes wounds are so large that healing by secondary intention or primary closure is not possible. A skin graft is a thin piece of skin usually taken from the thigh and is used to reconstruct wounds in the oral cavity or certain areas of head and neck skin. A skin graft has no blood supply of its own and is dependent on the wound bed for nutrients while new blood vessels grow.

- **Local or regional flaps**

A flap is any combination of tissues (skin, fat, muscle, bone) that has its own blood supply, unlike a graft. A local or regional flap is derived from tissues near the area that needs to be reconstructed. An example is the pectoralis major (chest muscle) flap to reconstruct the pharynx.

- **Free flaps**

A free flap is tissue taken from a distant site, such as the thigh (anterolateral thigh [ALT] flap) or leg (free fibula flap). Every free flap has an artery and vein that must be cut then re-attached to blood vessels in the neck. Without an artery bringing blood into the flap and a vein bringing blood out, the tissue will not survive. Free flaps allow for the reconstruction of large and complex defects.

Reconstructive surgery is an integral part of cancer care when a cancer operation involves the removal of tissue important for speech, swallowing, and appearance. There are a variety of techniques that can be tailored to meet a patient’s needs and improve quality of life.

Cancer - whatta, whatta, whatta...BLESSING!

By Glenn Brooks
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With a title like that, certainly you want to read a little further, primarily to figure out – okay, what is this guy on and where can I get some? Please let me explain...

In September 2011, I was diagnosed with Stage IV head and neck cancer, originating in the lingual tonsil. My treatment included chemotherapy, radiation, hydration therapy, tonsillectomy, feeding tube, extended stays in the hospital, and two and a half months of not being able to eat, drink, or speak. As I write this, I keep looking back at the title of this piece... cancer a blessing...really? Perhaps I am a bit crazy.

Let me set one thing straight – given the choice, I would have never welcomed cancer’s invasion of my body. Heck, I wouldn’t wish that on anyone. But the harsh, cruel, reality is this – cancer DID invade my body, and I have been given an opportunity, many opportunities if you would, to use that cancer experience to help others. THAT is the blessing...a divine calling. I genuinely believe that my calling is to seize as many opportunities as possible to reach out to others as they endure through treatments and recovery, as well as to thank those who have been fighting for the cancer patient – many times without the patient’s knowledge.

Mind you, this approach may not be for everyone – and that’s okay. Some cancer patients, as I have learned, wish to keep their experiences private...they just want the memories of that season in their life to quietly go away. Again, that’s okay. But for me, I choose to be an activist for cancer research, recovery and response.

Since I received the wonderful “no cancer in there” message in April of 2012, I’ve had the honor of volunteering in many capacities to reach out to others. I’ve been attending (as my schedule permits) the Head and Neck Cancer Support Group meeting in Bethel Park. I’ve become a member of the American Cancer Society’s Voice of Hope Program. I’ve become a member of the American Cancer Society’s Relay for Life Advisory Training Team. I’ve had the opportunity to share my article “10 Ways to Cope with Cancer” in the Winter 2012 edition of *Headway* as well as the national publication *Coping with Cancer*. And I’ve met some rather incredible folks along the way. The energy and passion that I’ve felt is nothing short of amazing. I can tell you this, with full confidence, we are loved – loved by people who don’t even know us.

Why so involved? In most of the cases, the speeches of hope and encouragement, the conversations and the relationships, the fundraising and events, really aren’t doing anything for me...on the surface. My treatments are done and my recovery is progressing swimmingly. But deep down, deep down in my inner self, my involvement these past months has allowed me to fulfill my destiny and thank those who were fighting for me/with me during my darkest moments. And, my involvement has given me the opportunity to thank all of those people who were fighting for US...each and every one of us who understands, intimately, the challenges that face the person who hears the words “you have cancer”. I do what I do for you! My voice becomes the voice of many.

I’ll never forget all of the people who were so wonderful to me – my wife and daughters, my family, my co-workers, my church...and the countless others. They too were so instrumental that I am driven to help others.

With each and every interaction that I have, from a one-on-one conversation to a speech before 800 high school students, I always, and on the behalf of all cancer survivors and their caregivers, thank those engaged in the fight. I encourage them to remain involved so that we can rid this world of cancer so our future generations never have to hear those words, and finally, I ask God’s blessing on them.

It’s all about three undeniably significant words – faith, love and hope.

My friends, I will continue to represent you and I will continue to remain involved. My self-centric days are over – and my others-centric days are before me. Thank you, and God bless you!

This issue we asked doctors and speech-language pathologists from UPMC Swallowing Disorders Clinic to answer some questions regarding swallowing problems in head and neck cancer patients.

What is dysphagia?

By Kara Davis

Resident in Otolaryngology, Head and Neck Surgery, University of Pittsburgh Medical Center

Dysphagia is the medical term for swallowing problems, which involves difficulty moving liquids, pills, or solids from the lips to the stomach. Normal swallowing function is a complex action that is practiced nearly every day of our lives. Cancer in any body part along this pathway almost always affects swallowing.

How are swallowing problems diagnosed?

We rely heavily on a team approach. There are different ways of diagnosing swallowing problems, but most patients undergo either a fiberoptic endoscopic evaluation of swallowing (FEES) test, a modified barium swallow (MBS) test, or both. During an FEES test the patient is asked to swallow dyed foods while the doctor and speech-language pathologist watch with a camera on the inside of the throat. During an MBS test, the patient swallows foods with barium dye while a radiologist and speech-language pathologist watch the swallowing by X-ray from the outside. In either test, food and liquids are considered “down the wrong pipe” if there is dye in or near the voice box, which is the top of the windpipe.

How do I know if I have swallowing problems?

Hints that suggest swallowing problems include changes in the voice such as a “wet” or “gurgly” voice, lung infections or pneumonias, weight loss, decreased interest in eating, and coughing, choking or gagging with eating or drinking.

Will it go away once my cancer is cured?

While your ability to swallow may not be as it was before cancer, many patients are able to learn how to swallow in a new and safe way which becomes a “new normal”. Some people are able to eat solid foods and drink liquids after head and neck cancer treatment. Others may consume a “modified” diet such as pureed foods. Humans learn to swallow as infants and practice this everyday by eating and drinking. A 50-year old patient who has eaten three meals a day has practiced eating a meal nearly 55,000 times. It takes patience and time to condition the swallowing muscles, nerves, and the brain to swallow in a new way.

What happens if dysphagia isn't treated?

Complications of dysphagia include malnutrition and pneumonia, which can be life-threatening. Dysphagia may also impact the enjoyment of day-to-day life.

What causes swallowing problems?

Both the cancer itself and its treatment can cause swallowing problems. Sometimes, patients first discover the cancer because of difficulty swallowing. Other times, the treatment of cancer by surgery and/or radiation can cause swallowing problems. Swallowing problems nearly always worsen during times of active treatment, such as radiation. Swallowing problems can persist or even worsen for years after treatment.

What exactly is swallowing therapy?

Swallowing therapy is personalized to each person's swallowing problems and strengths. Sessions typically include helping patients select food choices, learning exercises to practice to build strength and learn new habits, and implement to make swallowing safer and more comfortable. A course of therapy may include weekly meetings with the swallowing therapist for eight weeks, and independent practice several times daily. The patient often returns to the Swallowing Disorders Clinic for evaluation following treatment. Many patients continue independent practice for the rest of their lives.

If I have a feeding tube, do I need swallowing therapy?

Yes. Just like athletes practice before a game, patients can practice swallowing before there is actually food or drink. Patients

that practice swallowing, even without food or drink, may have a better chance of being able to have the feeding tube removed and take nutrition by mouth.

Does swallowing therapy really work?

Yes. A study at UCLA's Jonsson Comprehensive Cancer Center demonstrated that swallowing therapy decreased the likelihood that patients receiving radiation would need a feeding tube or suffer other unwanted swallowing side effects, versus similar patients not participating in therapy.

What is stereotactic radiosurgery?

By Jose L. Mattos, MD, MPH

Resident, Department of Otolaryngology, Head and Neck Surgery, University of Pittsburgh Medical Center

Treatment of tumors and growths are approached in different ways depending on their type and location. One common option available is radiation therapy. Standard radiation treatment delivers high-powered radiation with the goal of shrinking a tumor, or sometimes to control or slow down its growth, and uses multiple doses of radiation given over a prolonged time period. Over the past few years, a new type of radiation therapy has emerged called Stereotactic radiosurgery, abbreviated as SRS.

SRS is a type of treatment that uses focused beams of radiation to treat tumors and abnormal growths. The idea behind this therapy is to maximize the amount of radiation that is given to a tumor, while trying to minimize damage to the surrounding normal tissues. SRS achieves this by focusing multiple narrow radiation beams on one tumor. Each individual beam is not very powerful, and so does not cause much damage to the tissue that it goes through. However, when all of these beams combine on their target (the tumor), their combined power can now treat the abnormal tissue. In this way, SRS can give a high dose of radiation in a shorter amount of time and with greater accuracy than standard radiation treatments.

SRS began as a therapy used for brain tumors that were either too risky to remove surgically, or for which standard radiation would have caused too much damage to

continued on page 5

Stereotactic radiosurgery

continued from page 4

the surrounding brain tissue. However, recently SRS has begun to be used in many other types of tumors and cancers, including those in the head and neck. The head and neck, like the brain, have many important structures in close proximity to each other. These structures are critical to vision, speech, swallowing, taste, and overall appearance, and can be affected in the treatment of head and neck tumors.

SRS is well suited for head and neck cancer. When a patient presents with a head and neck tumor, the usual treatment regimen may involve a combination of surgery, radiation, and/or chemotherapy depending on the size of the tumor and the disease stage. How much radiation can be given in head and neck cancer is limited by how much radiation the nearby normal tissue can withstand. SRS is able to maximize the amount of radiation on a tumor while decreasing the radiation that normal tissue receives. This can be particularly useful in patients who have already had a full standard radiation treatment and then suffer a recurrence. In this case, the normal tissue has already received as much standard radiation as it can stand. SRS allows doctors to deliver more radiation to the recurrent tumor, and decrease damage to the important nearby structures that are not affected.

Despite its name, stereotactic radiosurgery is not a surgical procedure. There are no scalpels or incisions needed, so this means reduced risk of bleeding and infection for patients. There is also no need for general anesthesia or a breathing tube, so SRS eliminates the risks associated with anesthesia. This is important to patients who may be elderly, or have medical conditions that prevent them from undergoing general anesthesia. SRS patients typically go home the same day after the treatment is completed, although sometimes a hospital stay is needed.

There is currently much ongoing research in this field, and determining whether SRS therapy is right for you depends on many factors. Your doctor can have a personalized discussion with you regarding your treatment options. SRS may be a powerful alternative for patients with tumors in places that are difficult to treat or for those who have already undergone standard radiation.

The sacred work of caregiving

By Patricia Smith

Founder, Compassion Fatigue Awareness Project

Traditional caregiving practices are changing. The idea of one person taking full responsibility of providing care to another person is slowly fading away. In its place is a new concept embracing the idea of partnership, where both the caregiver and the person receiving care work together to affect help, hope and healing. This mode of care is particularly beneficial where cancer patients are concerned.

This new model of providing healthy care to others is emerging across the helping professions as well as with family caregivers. No longer is caregiving seen as a one-way street where a caregiver is put in the position of being traumatized by another person who is incapacitated, in pain, suffering or preparing to die.

True empathetic, compassionate care is now viewed as a two-way street. While being of service to another, a caregiver is called upon to be the receiver and bearer of the “gifts” the suffering impart to those who cross his or her path including medical professionals, family members, friends or religious. For a caregiver, there is much to be learned from cancer patients in pain and suffering, and preparing to die. And for those in pain, who are suffering and in the process of dying, there is a wealth of wisdom to be shared.

In 2000, an Oregon hospital inaugurated an in-house program called *No One Dies Alone*. The purpose of the program was to provide companionship and care to a dying patient when no family members or friends existed or couldn't be present. Often, the need for this service is requested by a member of the chaplain services staff who is called in to comfort the patient or, in Catholic hospitals, provide Last Rites. Compassionate Companions, as these program volunteers are called, receive training and schedule caregiving rituals where they are present onsite with the patient anywhere between 1-36 hours. The program caught on and is now offered throughout hospitals and hospices nationwide.

In my health care public relations work, I interviewed a number of associates who volunteer for the *No One Dies Alone* program in one of the hospitals where I

serve. What I learned was surprising to me. Every volunteer told personal stories highlighting the life-affirming gifts that flowed between caregiver and patient. Incidents of trauma appeared to be at a minimum and in its place was a spirit of love, empathy and compassion. At the end of each interview, I asked the caregiver what he or she did to provide authentic, sustainable self-care in order to lower levels of compassion fatigue and continue to do the intense work they do. Many offered ideas such as walking in the woods, being with loved ones, or enjoying hobbies such as fishing or journaling. One of the chaplains answered in this way, “When I hold the hand of a dying person, I am filled up”.

In the new mode of caring, a cancer patient would hold up his end of the process and take an active role in allowing his life, no matter how debilitating, to retain a level of quality and dignity. This includes completion of advance directives, wills, organ donation forms, and other end-of-life documents to help family members avoid heart-wrenching decisions. Patients are asked not only to appreciate and value the care they are receiving, but they are also being asked to reciprocate in kindness, patience and respect.

This new model is based on the idea that a patient actually enters into a healthy caring relationship with his or her care providers. The relationship is based on respect, trust and honesty – a partnership where everyone involved does his or her best to create both a culture of curing and a culture of caring.

The Compassion Fatigue Awareness Project (www.compassionfatigue.org) presents workshops nationwide educating caregivers in all the helping professions on how to recognize and manage compassion fatigue. Patricia Smith is the author of the award-winning book “To Weep for a Stranger: Compassion Fatigue in Caregiving”, along with other training materials available on Amazon.com.

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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