

HEADWAY

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

PAGE 1

Solving the puzzle of head and neck cancer with personalized medicine

PAGE 2

The Yellow Kayak

PAGE 3

UPMC Hillman Cancer Center partners with Wellist to connect patients to non-medical support services

UPMC establishes Pittsburgh CREATES

PAGE 4

The importance of dental care before, during, and after treatment for head and neck cancer

PAGE 5

Survivorship: enhanced approach to provide supportive care for survivors of head and neck cancer

PAGE 6

Swallowing Disorders Center

Clinical trials

Contact information

Head and Neck Cancer Program website

Solving the puzzle of head and neck cancer with personalized medicine

By Heather Chronis

Director Patient Relations and Development Officer, Eye and Ear Foundation



Dr. Robert Ferris

Robert Ferris, MD, PhD, has always had an interest in diseases that are difficult to conquer, both in the clinical arena and in the research laboratory. As a medical student at Johns Hopkins University in the 1990s, Dr. Ferris was intently studying HIV and trying to find answers to the virus's unique features. "I have always been interested in diseases that are like a puzzle. How do you move the pieces around to put the whole picture together and answer the question?" states Dr. Ferris. However, a new medical puzzle emerged while he was still in school - human papilloma-virus (HPV) and, specifically, its role in cancer of the head and neck.

It had been thought for years that smoking and drinking were the greatest precursors to head and neck cancer. The team at Johns Hopkins began to see an uptick in head and neck cancer patients that also tested positive for HPV. While the numbers of patients with HPV were increasing, this was also the patient group that had better outcomes for overall survival with head and neck cancer. Intrigued by this new piece of the puzzle in head and neck cancer, Dr. Ferris turned his focus to discovering more about this rapidly emerging new factor.

Cancer has traditionally been treated with four different options: surgery, chemotherapy, radiation and, now, immunotherapy. Physicians were cautiously optimistic with the potential outcomes of each of the four options, but there was always a variability factor - why did some patients recover, while others with the same type of cancer did not? Immunotherapy, a treatment designed to boost the body's natural defenses to fight cancer, uses substances either made by the body or in a laboratory to improve or restore immune system function. It can stop or slow the growth of cancer cells, along with preventing the cancer from spreading to other parts of the body. In addition, it can assist the immune system to better destroy cancer cells. Immunotherapy is non-invasive and has the least amount of side effects of the four cancer treatment options. Testing positive for HPV adds another factor into the immunotherapy treatment plan. For example, the HPV vaccine has shown promise in combination with cancer drugs in head and neck cancer patients that test positive for the virus.

continued on page 5

The Yellow Kayak

By Howard B. McDaniel

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

When I realized I might be on a feeding tube for the rest of my life, I sat down and had a long talk with myself. I had to decide how I wanted to live. The way I saw it, there were only two choices. I could accept it as a lousy predicament, engage the world, each day an adventure, moving on, as effectively as possible. Or, I could feel sorry for myself, withdraw from the world, allowing every inconvenience, every frustration to feed an anger that I knew had the potential to consume me. So much depended on my choice. Not only for me but for those who loved me. It was a choice of participating in the world or losing myself to a self-imposed exile to a small and narrow world of my own selfishness. It was a choice of giving up or moving on and I chose to move on with my life.

Almost immediately, I resumed doing the things I enjoyed doing. I began working in the yard, setting stones on my rock walls, splitting wood, and kayaking, albeit slower and with less strength and stamina, but in the end, with the same result - the joy of doing something I love and the satisfaction of doing something well. I soon acquired a small portable infusion pump and backpack and learned how to step up the infusion rate, reducing my three daily feedings to seventy-five minutes each, using the time to read, catch up on emails or explore the web. I began going places, doing things, and seeing friends, no longer using a feeding tube as an excuse to stay home. I'm not saying it was always easy. I had to plan ahead, be flexible, ready for the unexpected, unbothered by insignificant things, or concerned about

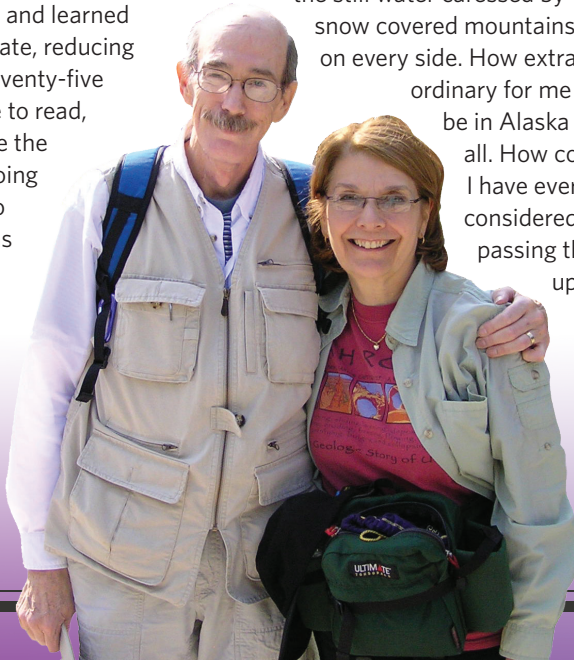
a little embarrassment. I had to keep speed bumps in perspective and not let them overwhelm me. In a sense, I had to be relentlessly intolerant of every urge to overreact to trivia.

When my wife, Lyn, and I flew to Los Angeles to visit our granddaughter, we encountered horrendous flight delays as well as problems shipping my liquid food across country. Nevertheless, we learned enough about traveling with a feeding tube that two months later we flew to Anchorage, Alaska, rented a Jeep, and spent twelve wonderful days visiting Alaskan national parks, fulfilling our dream of visiting all fifty states. We hiked in the back country, took a bus trip ninety miles into Denali National Park, a boat tour through Kenai Fjords National Park, and kayaked across a pristine wilderness lake serenaded by the haunting sound of loons. How extraordinary to glide across

the still water caressed by snow covered mountains on every side. How extraordinary for me to be in Alaska at all. How could I have ever considered passing this up?

Yet, the reality is that it doesn't matter whether I am kayaking with Mt. McKinley in the distance, or on the nearby Allegheny Reservoir. What matters is doing it. My arms, legs and mind are fine. So what if I have a peculiar eating regimen? I am alive and personally I can think of plenty of worse things than having a feeding tube in my belly. The speed bumps that occasionally get in my way are nothing more than opportunities for me to learn something. And isn't learning, growing, if you will, in the end, what it is all about? Isn't that how we become better people? Isn't that how we learn how to better cope with the challenges thrown our way? I didn't choose this predicament but I am determined to make the most of it, and to not let it rob me of one moment of joy from the rest of my precious time on this amazing Earth.

Yet, again, I am an imperfect man in an imperfect world. And I know that how I choose to look at things, and how I adapt, has a profound bearing on what I get back. I know there are no perfect solutions just as there are no perfect situations. But I know for me, looking at things honestly, head on, with never ending focus on the wide view has everything to do with the quality of my life. It is indeed an adventure and for me, I intend to step eagerly into every day. And if you are unable to find me some crisp sunny afternoon - well, I'll be on the reservoir, in a yellow kayak paddling alongside Lyn, urged forward by the delight of another gorgeous summer afternoon.



UPMC Hillman Cancer Center partners with Wellist to connect patients to non-medical support services

One-stop resource improves patient experience, saves staff time

By Ann Toomey
Wellist Marketing

Because 40% of health outcomes are tied to social drivers, Wellist was designed to help patients, caregivers and staff easily find important support services. Wellist consolidates thousands of vetted, national and local vendors with UPMC resources; the result is an online directory that features 2,000 plus services in over 20 categories ranging from transportation and meal delivery to financial assistance and support groups. The directory, which includes free, discounted and fee-based offerings, matches services to a patient's location, condition and specific needs. For example, following surgery, Julie would like to connect with an online or phone-based head and neck support group since she is unable to attend in person. She may also need low-sodium meals delivered to her home in Moon Township. Wellist will connect Julie to services that exactly match her request.

Once patients and caregivers choose their services, they can share their personalized recommendations with family and friends, who can then contribute to get their loved ones the help they need most. To learn more, visit upmc.wellist.com or call 855-WELLIST (935-5278).

FREQUENTLY ASKED QUESTIONS

How does Wellist work?

Wellist sorts through thousands of services to match the right ones with patients' and caregivers' unique needs. Patients and caregivers can sign up online, by phone, or in-person with a Wellist representative. Access to the Wellist directory is offered as a complimentary service demonstrating

UPMC Hillman Cancer Center's commitment to patients, caregivers, and staff.

Are these services free?

While many of the services recommended are free, subsidized, or discounted, others require an out-of-pocket payment. For those vendors with a fee, \$ - \$\$\$\$ will be displayed to indicate relative cost.

Can patients get help paying for these services?

Yes. Once patients and caregivers receive their personalized recommendations, they can share their support plan with family and friends. If they choose, family and friends can contribute to help the patient or caregiver get the services they need. Each contribution goes directly into a PayPal account linked to the patient or caregiver's email address. Wellist does not take a fee.

Can Wellist provide support for patients who don't live near their treatment center?

The Wellist directory includes vendors covering Allegheny County, as well as hundreds of national services. Patients can choose services close to their home or their treatment center.

UPMC establishes Pittsburgh CREATES

By Jonas T. Johnson, MD
Chair, Department of Otolaryngology, Eye and Ear Institute

The Collaborative for Research, Education And Technological Enhancement in Surgery will be located on the first floor of the Eye and Ear Institute Building. CREATES will facilitate collaboration of surgeons and engineers with representatives from a variety of companies to work together to enhance efforts to improve minimally invasive surgery. The improvements introduced to surgical care in the last several decades have revolved around the use of small incisions to do major surgery. This has been made possible by advanced lighting systems that can be placed on telescopes. The introduction of many new and improved miniaturized tools allow surgeons to remove tumors, control bleeding and make repairs without actually having to get their hands into the wound.

At the University of Pittsburgh, a collaboration initially established in 1990 between ear, nose and throat surgeons, neurosurgeons, engineers, and companies which make these tools has led to a completely new approach to removal of tumors in the brain. Prior to the introduction of this minimally invasive approach, brain tumors could only be removed through large incisions in the scalp with removal of bone to allow the surgeons access to the brain tumor. The minimally invasive procedures require the use of specialized telescopes which allow surgery through the nose, offering the opportunity for surgeons at the University of Pittsburgh to introduce an entirely new approach to remove brain tumors. This type of surgery has been improved over the course of the past 25 years such that hundreds of surgeons from around the world regularly come to Pittsburgh to learn these techniques.

You have also heard that there currently are surgical robots that allow major procedures to be done through very small openings in your skin. A collaboration between surgeons and engineers led to the development of a snake robot which can be inserted through a normal body opening, such as the mouth, to do delicate operations deep in the throat. The advance attributable to the snake robot is the ability of the surgeon to advance the fiberoptic telescope around corners and to operate on a target which is not directly in front of the telescope. This of course required development of instruments which can be deployed around courses as well as special training in this kind of surgery.

Surgeons at the Eye and Ear Institute and across the academic medical center are now collaborating to enhance research in minimally invasive surgery. CREATES will focus on research and education. As new instruments are developed and new techniques to do procedures are discovered it becomes essential that opportunities for training and practice in the laboratory be made available before these techniques are actually employed in the operating room. We are optimistic that CREATES will mark yet another milestone in advances in surgical care which have originated here in Pittsburgh.

The importance of dental care before, during, and after treatment for head and neck cancer



Dr. Antonia Teruel Castellon

By Antonia Teruel Castellon DMD, MS, PhD
Assistant Professor, Department of Diagnostic Sciences,
University of Pittsburgh School of Dental Medicine

The majority of the population knows that brushing and flossing are important in order to maintain healthy teeth and gums. On

the contrary, the importance of oral health seems to be understated for patients that will be or have been treated for head and neck cancer.

Head and neck cancer treatment often results in the destruction of the cancer cells. Unfortunately, cancer treatment, mainly radiotherapy, may be accompanied by undesirable effects including dry mouth, difficulty to eat and swallow, inability to completely open the mouth, and poor bone healing. From these, dry mouth is the most common oral complication of head and neck radiation and one that has a great impact on talking, eating, and teeth integrity. Saliva is not only important to keep your mouth moist, it also has other indispensable functions:

- it lubricates food for easier swallowing,
- it promotes oral cleansing,
- it helps in our sense of taste
- it protects against dental cavities by recoating the teeth with minerals,
- it prevents oral infections by protecting the mouth and throat from oral microorganisms, such as bacteria, viruses, and yeast

Patients with decreased production of saliva feel their mouths uncomfortably dry and are at high risk for quickly developing tooth cavities, gum disease, and thrush. Moreover, radiation to the head and neck results in the increased risk of developing osteoradionecrosis (ORN) of the jawbones.

Owing the risk for complications, it is crucial that excellent dental hygiene is emphasized even before starting cancer treatment, especially radiotherapy. You

should work with your dentist before, during, and after treatment. Below are the steps that you, along with your dentist, need to take with the purpose of achieving optimal oral health and thus, prevent dental cavities, eliminate any source of dental infection, manage symptoms of dry mouth, and prevent ORN.

Oral care prior to starting chemotherapy and/or radiation therapy:

Before starting your chemo and/or radiation therapy, visit your dentist and let him/her know that soon you will be starting treatment for cancer. Your dentist should then proceed to do a thorough oral exam to identify potential problems. According to your needs you may be receiving oral hygiene instructions, nutritional counseling, cessation of tobacco and alcohol use.

One of the main goals of this visit is for you to have a deep cleaning in addition to treat any existing infections and eliminate potential sites of infection and trauma such as filling any cavities or adjusting any ill-fitting dentures. Also, during this appointment your dentist will take impressions to fabricate a custom tray that you will be using to apply fluoride.

Keep in mind that if you need any tooth to be extracted (pulled) it should be done at least 2 weeks prior to the initiation of radiation and chemotherapy to allow adequate time for the bone to heal.

Oral care during chemotherapy and/or radiation therapy:

During your treatment, your mouth might become sore and you may have painful ulcers. Nonetheless, oral care is still important and you should try to continue with your routine as long as you can tolerate it.

To prevent hurting your gums use an extra-soft toothbrush and floss gently. If you are not able to tolerate brushing you

can use a damp gauze to wipe your teeth. Additionally, reduce the use of removable dentures as much as possible to avoid further trauma to your mouth.

In particular, patients receiving radiation therapy should use their custom trays to apply fluoride once a day and do stretching exercises of the jaw muscles daily to prevent/reduce trismus.

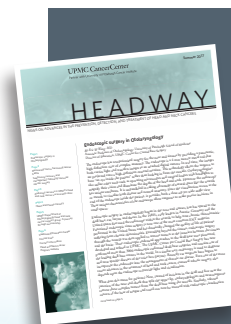
Oral care after chemotherapy or radiation therapy:

Two weeks after your treatment has finished and once all treatment side effects are resolved, you can resume your routine oral care with some extra preventive measures. For the rest of your life you will need to brush and floss after each meal and avoid sugars. Daily use of fluoride is crucial, so you should continue to use your trays. Your dentist can prescribe you a toothpaste with a high concentration of fluoride for you to brush at night.

To manage your dry mouth, take constant sips of water and use saliva substitutes. There are several over-the-counter products available in drug stores. Choose the one that works best for you.

Since you are now at higher risk for developing cavities and ORN, you should visit your dentist more often (every 3-4 months), since these can happen very quickly in patients with dry mouth.

Taking care of your teeth and mouth will require more time than before cancer treatment and will be necessary for the rest of your life. Maintaining perfect oral care is critical for your quality of life and for preventing more serious complications.



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

com/portal_headneck/publications.cfm for archived issues of Headway.

Head & neck cancer support groups

- A cancer support group, primarily for head and neck cancer patients, family members, and caregivers 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.
- The SPOHNC (Support for People with Oral and Head and Neck Cancer) support group meeting is held the second Tuesday of each month from 2:30-3:30 pm., 203 Lothrop Street, Eye & Ear Institute, 5th floor, Pittsburgh, Pa. 15213.

Survivorship: enhanced approach to provide supportive care for survivors of head and neck cancer

By Marci L. Nilsen, RN, PhD and Jonas T. Johnson, MD, Chair, Department of Otolaryngology, Eye and Ear Institute

Every year healthcare professionals treating cancer of the head and neck in Allegheny County encounter hundreds of new patients. People present with hope for a cure and for the opportunity to continue living a happy and productive life. Over the past ten years, we have an increase in head and neck cancer associated with the human papilloma-virus, which presents in younger, healthier individuals. Unfortunately, while modern medicine helps us cure more patients, it has not achieved the goal of returning patients to their preexisting state. Treatments are intense and long-lasting side effects occur, especially

when radiation is required. The addition of chemotherapy to radiation makes the irradiation more effective; unfortunately, it also makes it more toxic.

The UPMC Head and Neck Cancer Survivorship Clinic first began seeing patients at Eye and Ear Institute in December 2016 and to date, we have seen over 350 individuals. The clinic team includes a head and neck surgeon, nurse, speech-language pathologist, physical therapist, dentist, and audiologist. If patients have not started treatment, we provide them tailored assessment, education, and arrange for them to get help, especially with swallowing, during treatment. For patients who have completed treatment, we perform a comprehensive review of treatment-related changes, identify therapies that can help improve their functioning, and assist with coordinating care. At the end of each visit, we provide all patients with a summary of their treatment and personalized recommendations for care. This summary and care plan is also sent to the other healthcare providers including medical oncologist, radiation oncologist, and primary care providers.

Our observations confirm that the treatment is harsh and recovery takes months. To date, we have seen 271 patients who have completed treatment, on average, five years ago. The people evaluated were primarily men (72%) who were approximately 65 years of age. An astonishing 89% of patients report at least one treatment related change which has affected their daily activities in the last seven days and over 50% of patients report at least three treatment related side effects. Symptoms of major depression have been reported by 19% of patients while 14% report generalized anxiety. The most prevalent and most important patient reported symptom has been difficulty swallowing. Unfortunately, nearly 60% of patients also report neck disability and pain.

These observations are important and serve to sound an alarm for our professional team who seek to provide support and care for individuals who have experienced head and neck cancer and want to return to their life. Our team provides an opportunity for comprehensive evaluation and treatment recommendations. We are open and happy to accept referrals and new patients. We have made an effort to make a visit to the survivorship clinic as affordable as possible. Patients are offered the opportunity to see all our specialists for a single visit payment. Under most circumstances, this results in a single co-payment. People who require therapy, need an x-ray or CT or a visit to another dentist will encounter payment obligations as appropriate.

Survivorship Clinic: 412-647-2100

Solving the puzzle of head and neck cancer with personalized medicine

continued from page 1

As Vice Chairman of the Department of Otolaryngology at the University of Pittsburgh School of Medicine and Director of the Marion S. Mosites Initiative for Personalized Medicine, Dr. Ferris is on the forefront of immunotherapy research that offers hope for head and neck cancer patients. What

Dr. Ferris, who is currently involved in three clinical trials, and others have discovered is that, while some patients

might all have the same type of cancer, each might have a tumor that responds totally differently to treatment, therefore, that one standard protocol is not effective in saving lives or even maintaining a good quality of life. The Mosites Initiative has provided the funding necessary for specific immunotherapy research, which can often have unpredictable outcomes. While government and corporate funding are important to research efforts, traditionally they require a logical

outcome from the research. With cancer research, the outcomes are often illogical. "Positive and negative outcomes of research are good things. Obviously, we want positive outcomes, as it helps the patient, but negative outcomes send us in a different direction. This is why private philanthropy is critical, as it allows us to find out the positive and the negative of a treatment with the end goal of better patient outcomes," states Dr. Ferris.

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.

Head and Neck Oncology Eye & Ear Institute

203 Lothrop St., Ste. 300
Pittsburgh, PA 15213
412-647-2100

Head and Neck Cancer Program UPMC Hillman Cancer Center

5150 Centre Ave.
Pittsburgh, PA 15232
412-647-2811

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Christine A. Platania

Head and Neck SPORE
Grant Administrator

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
Heart and Hands Ministry.....	724-935-3636
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.....	UPMCHillman.com/headandneck

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 Program of UPMC Hillman Cancer Center at UPMCHillman.com/headandneck.