

HEADWAY

SINCE 2007

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

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One size doesn't fit all

By Carrie Fogel

Director of Development, Eye & Ear Foundation

Broadly defined, personalized medicine is a 'one size doesn't fit all' approach to medicine in which physicians use diagnostic tests combined with genetic information to determine which medical treatments will offer patients the highest chance of success while also considering what treatments may not be worth pursuing. The theory is that this type of individualized attention leads to more accurate diagnoses, earlier and more effective intervention, and more efficient drug therapies.

The physicians and surgeons working in the Department of Otolaryngology at the University of Pittsburgh have been using personalized approaches to treat cancers of the head and neck for several years. The Department has long been the recipient of a SPORE grant from the National Institutes of Health which is aimed at improving the prevention, detection, and treatment of cancer. An Eye & Ear Foundation fund, the Marian Mosites Initiative for Personalized Medicine in Head and Neck Cancer, generously established by the Mosites Family, has provided support to the Department for nearly five years.



Dr. Umamaheswar Duvvuri has treated patients with cancers of the head and neck for more than a decade, and is working, both in surgical innovation and basic science, to offer better options to patients going through such a difficult form of cancer. One area that interests him is understanding why some patients are cured and why others develop a recurrence. "We have people with early stage cancers that should be cured with conventional treatments, surgery, chemotherapy and radiation, and most of them will be cured, but some will unfortunately perish because of their disease. We want to know what is it about these patients who do not survive after treatment?"

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Dr. Uma Duvvuri is giving trainees instructions during a surgical procedure.

A journey through cancer

By Lori Arend

I woke up from sleep at 1:30 am on July 20th, 2018 with a need to go to the bathroom. I noticed my lips were tingling, twitching. My chin was numb. My eye lids opened and closed. Intense pain radiated in my head. Never before had I experienced these sensations. I thought: did I have a stroke? Bleeding in my brain? Was I going to die? I wanted to tell my daughter Maddie what I was experiencing but I had trouble speaking. I woke my daughter. She looked up at me and saw I was in distress. She called 911 and told the person on the phone my symptoms. When the paramedics came, I was able to speak more clearly. I was taken by ambulance to Passavant Hospital where they took CT and MRI scans. I was admitted to the hospital for observation.

A few days later, I was told by a neurologist the tests showed low-grade glioma, most likely a cancerous tumor requiring surgery. While handing me a business card, he said: "Don't worry, you're in good hands, call Dr. Raymond Sekula for an appointment." Boy was I relieved. When we went to see Dr. Sekula, I was so nervous and scared that I couldn't think of what I should ask the doctor. Fortunately, my daughter Valerie, an oncology nurse at UPMC Shadyside, asked questions and helped me understand what needed to be done.

At first, I was overwhelmed, but I had a better understanding of where I needed to put my focus. My prayers became more specific about where I needed help, so I prayed for strength to get through the surgery, radiation, and chemo. Guess what, it worked! I redirected my prayers and intentions and made it through every scary treatment and procedure.

Surgery was scheduled for August 24th, 2018 at UPMC Presbyterian Hospital. I was so nervous the night before and the morning before the surgery. While in the prep area, I was told I would be awake during the entire procedure. WHAT?

Although Dr. Sekula had mentioned this to me when we first met, it didn't register in my brain. Then I asked Dr. Sekula how long the surgery would last. He said: "about four and



Lori Arend (center) with her daughters Valerie Burgess (left) and Maddie Mastic (right).

one-half hours." I took a deep breath and thought: "I have to do this or I'll die." For 4½ hours, an attendant held my hand and said "you have to talk to him the entire time." Whenever I would not talk, he would shake me and we'd talk about anything that came to mind. Afterwards he asked me how I was able to talk for the entire time of the procedure. I told him "that's my job. It's what I do all day. I talk to people and try to keep them calm and centered." He said "It's nice to see you practice what you preach."

During the surgery, laying on my side, I could see all that was taking place. A clear plastic sheet was in place. I could see the doctor's face and the instruments used to remove the tumor. I could also hear all the sounds. It was a little overwhelming. About 90% of the tumor was removed. The biopsy showed a grade three astrocytoma. Everyone involved in my procedure was so kind and caring. I was in great hands.

I was told the recovery from the surgery would take from six to eight weeks before I could return to work. When I went back for the two-week check-up, I asked Dr. Sekula to please let me go back to work much sooner. He asked what I did at work. I told him "I sit in a chair and talk all day. I don't do well when I'm not busy." I returned to work three weeks after the procedure.

Approximately two months later, I began six weeks of radiation and chemo treatment. First I was fitted for a mask. It was made from a green plastic mesh and was molded to my face for radiation treatment. These sessions lasted for

about 30 minutes. I went Monday through Friday for six weeks. Every day they put that mask on and bolted the mask with my head in it to the table. This caused me so much anxiety I had to take medicine to calm down before each treatment. I was so worried about not being able to swallow or breathe, I just wanted to jump off the table. I talked to my doctor and he prescribed an anti-anxiety medication that helped with my anxiety. I thought, after I'm done with radiation, I'm going to burn this scary thing. Through the course of treatment and making it through I decided to keep my mask as a small memento of some of the toughest things I've gotten through.

During radiation I came up with a little ritual that kept me inspired. Each morning, I read some spiritual material, and wrote my experiences in a journal. I read somewhere not only write the negative experiences, but also the positive ones. So I put the negative ones in the back of the journal. The positive ones went in the front. My chemo treatment ended in December of 2018.



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.

My family and friends were there for me every step of the way with constant prayers, cards, phone calls, rides, whatever was needed. I can't forget to mention my co-workers at Laroche. The day of my surgery, they all gathered together wearing purple, with signs that read "sending love and healing Lori!". They took a picture and sent it to my family. We all cried.

Looking back, it's amazing to me how easy this experience has been. And I really do know that it's a God thing. He has me covered through everything I have faced and everything I will face in the future.

Annual Head and Neck Cancer Survivorship Symposium

The Department of Otolaryngology held its annual Head and Neck Cancer Survivorship Symposium on August 5-6 at UPMC Shadyside. The event was attended by almost 100 individuals and representatives of the media.

The symposium keynote speakers included: Mark Chambers, DMD, MS from the University of Texas MD Anderson Cancer Center; Julia Rowland, PhD of Georgetown University Medical Center; Evan Graboyes, MD from the Medical University of South Carolina; Timothy McCulloch, MD of the University of Wisconsin School of Medicine and Public Health; Teresa Hagan Thomas, PhD, RN; and Karen Losego, PT, DPT,

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.
- **Let's Talk Laryngectomy Support Group** – Meetings are held the first Tuesday of each month at 7:00 pm, Forbes Regional Hospital, 2570 Haymaker Road, Monroeville, Pa. Contact: Rich Boguszewski at rbogos@gmail.com or Dan Evans at djevans222d@gmail.com. <https://LetsTalkGroupPgh.wixsite.com/LaryngectomyHelp>.

CLT-LANA of the University of Pittsburgh. Topics included challenges of survivorship, self-advocacy in cancer care, contemporary therapy, rehabilitative strategies, strategies for oral health managing, and dysphagia.

The Head and Neck Cancer Survivorship Clinic at University of Pittsburgh Medical Center is a multidisciplinary model of care that allows cancer patients to see specialists, such as an audiologist, a dentist, a swallowing therapist, a physical therapist, a primary care physician, and a surgeon, all during one clinic visit under one copay. This model provides consistent, comprehensive follow-up care for patients and allows doctors to better understand and treat patient needs.

"Over 90% of our cancer survivors report having to deal with a side effect in the past seven days, and over 50% report dealing with three or more," states Jonas Johnson, MD, FACS, Professor and Chairman of the Department of Otolaryngology. "This 'cost of care' has been largely overlooked. Our efforts have

brought awareness to these problems and afford opportunities to better understand avoidance, treatment, and prevention."

During the symposium a panel discussion was held featuring Marty Griffin, a local reporter and head and neck cancer survivor, his wife Kristine Sorensen, and Marci Nilsen, PhD, Assistant Professor of Otolaryngology and Coordinator of the Head and Neck Cancer Survivorship Clinic.

"In my life I've never been around folks like this, from the doctors who perform the surgery, to the nurses at Hillman [Cancer Center], to the people at the survivorship clinic, and I've never seen something like that," says Griffin, who was diagnosed with head and neck cancer in 2018 after discovering a lump on his throat. "Within five days of my initial biopsy I had robotic surgery with Dr. Bob Ferris."

Wanting to use his platform as a public figure for good, Griffin chronicled his cancer journey online and became an unofficial spokesperson, advocating for people to get vaccinated against the human papillomavirus (HPV), which precipitated his own cancer.

"He really wanted to be public about it and in retrospect it was the best thing we ever did," says Sorensen, who is also a local news reporter for KDKA. "It feels so good to be able to help people and give all of this a bigger purpose."

Serving a bigger purpose is at the center of the survivorship clinic, as researchers and clinicians work together to advance care for patients who often face uphill battles even after surviving their initial cancer diagnosis.

"We need funding to continue to both aid in optimizing patient care, but also evaluating new approaches to care,

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The winners of the best poster competition held during the Survivorship Symposium are (left to right) Dr. Florence Wright, Dr. Charlene Williams, Michael Belsky, Barbara Ebersole and Kathleen M. Donocoff, MS, CCC-SLP.

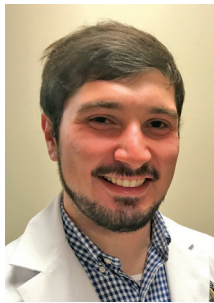
which we mainly do through research,” says Nilsen. “Once we identify the issues, we can test ways to mitigate these changes.”

The 2020 Survivorship Symposium will be held on August 3-4, 2020 at Herberman Conference Center at UPMC Shadyside.

Recognizing caregiver burden

By Zachary Kassir

Medical student, second year



Head and Neck cancer is a debilitating illness that presents a wide range of difficulties for patients. In the United States more than 53,000 people are

diagnosed every year with 10,800 dying from the disease. Head and neck cancer is often treatable and many people are even cured, however the treatment can cause profound side effects. Surgeries to remove cancer from the head or neck can leave people with significant disfigurement or with the need to breathe through artificial openings in their necks for the rest of their lives. Radiation therapy can cause weakening and scarring of mouth and throat muscles as well as the destruction of the tissues that produce saliva. This impairs a patient's ability to swallow and can sometimes make eating and drinking impossible. In such cases, a patient relies on a feeding tube that is implanted directly in their abdomen for nourishment. Senses of taste and smell can also be affected by radiation therapy, sometimes permanently.

Recovering from head and neck cancer and its treatment is immensely challenging, and patients often require a great deal of physical and psychological support. As such, the importance of a good caregiver cannot be overstated. A caregiver is anyone (a spouse, parent, child, sibling, or friend) who assumes a significant amount of responsibility for taking care of a person who is undergoing treatment and recovery for an illness. In cases of head and neck cancer, a caregiver can have a great variety of

responsibilities that may include helping their loved ones to maintain their breathing and feeding tubes, preparing food that they are able to eat, assisting them to carry out physical rehabilitation tasks, and providing constant emotional support.

Due to their immense responsibilities, caregivers face a great deal of physical and psychological burden themselves throughout their loved one's treatment and recovery. In a 2012 study done at Temple University more than half of caregivers (for people with head and neck cancer) reported a need for professional psychological care. Of those caregivers whose loved ones had undergone surgery, 40% met the criteria for a clinical anxiety disorder. A 2013 study done at Northwestern University's Feinberg School of Medicine had similar findings with 38% of caregivers reporting moderate to severe emotional distress. It also appears that caregivers often feel unsupported and unequipped to carry out many of their responsibilities. In the same 2013 study, only 39% of caregivers reported that their practical and informational needs were being met, while a 2016 survey study done at Vanderbilt University found that almost all caregivers experienced severe discomfort performing at least one of their responsibilities.

It goes without saying that caregivers are personally deserving of freedom from crippling distress. At the same time, their quality of life dramatically impacts their ability to support their sick loved ones. Lower rates of distress among caregivers for serious illnesses like Alzheimer's disease and brain cancer have been associated with lower rates of mortality among patients as well as shorter hospital stays and longer periods of time before placement in assisted living facilities. Predictably, patients themselves are also less distressed by not having to watch their loved ones sacrifice their well-being to care for them. One can assume that these trends would hold for head and neck cancer as well.

Limiting the burden and distress that caregivers experience means improving the outcomes of the patients they care for and minimizing the strain that is put on the health care system. This fact should motivate more research on head and neck cancer caregivers and the

burdens they face so that we can develop measures to promote their well-being. It should also serve to remind us all that when we are sick, those who take care of us often suffer with us, and that the healthier they are, the sooner we can expect to be healthy ourselves.

A Dietitian's role in head and neck cancer

By Angela Zaccagnini, MS, RD, LDN
Clinical Dietitian, Specialist
UPMC Hillman Cancer Center

A registered dietitian-nutritionist in a hospital or cancer center works as a healthcare professional alongside the team to manage a patient's diet before, during and after treatment. When it comes to cancer and cancer therapy, nutrition is so important and often overlooked. The main goal for the dietitian is to optimize a patient's nutrition status and provide nutritional support throughout their journey. With a head and neck cancer diagnosis it can be particularly hard to maintain good nutrition due to all the symptoms and side effects associated with treatment. A dietitian can help provide appropriate food choices and make recommendations to maximize nutrition status and promote healing. The common symptoms that occur with head and neck cancer are decreased appetite, taste changes, thickened secretions, dry mouth, difficulty swallowing or dysphagia, and gastrointestinal issues such as nausea, vomiting and diarrhea. All these symptoms can result in weight loss and malnutrition which can cause weakness, fatigue and even treatment interruptions.

During treatment, energy needs increase which means daily calorie and protein requirements are higher than normal to promote weight maintenance. Weight maintenance is the number one goal for patients receiving treatment because this assures adequate nutrition. Food is what provides energy and reduces those feelings of fatigue and weakness. The typical recommendations from a dietitian are to consume small but frequent nutrient-dense meals and snacks to receive adequate calories and protein throughout the day. However, because of all the side effects, certain foods and beverages work better than others.

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The prevalence of insomnia and its association with psychologic symptoms and quality-of-life in cancer survivors

By Jonas T. Johnson, MD, *Chair, Department of Otolaryngology, Eye and Ear Institute;*
Marci Lee Nilsen, PhD, RN, *University of Pittsburgh, School of Medicine, Department of Otolaryngology, Pittsburgh, Pa.*

Sleep disturbance is commonly encountered in cancer patients. It has been previously reported that poor sleep quality results in a decrease in quality-of-life as well as an increase in both anxiety and depression. These issues have not been carefully explored in patients with cancer of the head and neck.

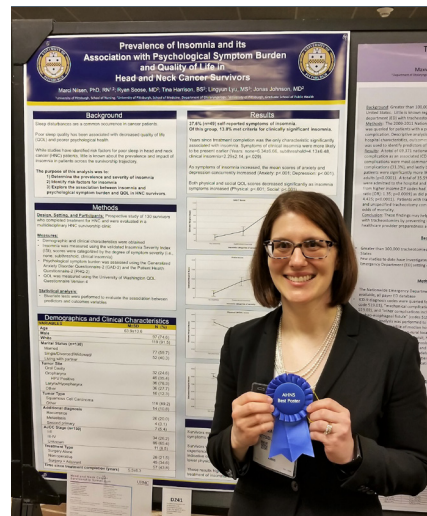
A team led by Marci L. Nilsen, PhD, RN, CHPN recently won a blue ribbon for their poster presented at the annual meeting of the American Head and Neck Society, May 2019, Austin, Texas. Dr. Nilsen and her colleagues conducted a study of patients evaluated in the UPMC Head and Neck Cancer Survivorship Clinic. A total of 130 survivors of head and neck cancer responded to several patient-reported outcomes questionnaires. Insomnia was measured using the Insomnia Severity Index, a questionnaire which has been validated as a sensitive and accurate way to determine if a sleep disturbance exists. We also asked about the psychological symptom burdens of anxiety and depression. Quality-of-life was measured using a University of Washington Quality of Life measure, which has been validated

by other investigators and commonly administered to patients with head and neck cancer.

Almost 40% of the patients surveyed reported symptoms of insomnia. Symptoms of insomnia were more prevalent soon after diagnosis. With the passage of time, people reported fewer symptoms of insomnia. As people experienced increased symptoms of insomnia, both anxiety and depression increased concurrently. It was also found

that both physical and social-emotional quality-of-life scores decreased as insomnia symptoms increased.

These results highlight another important need for the head and neck cancer survivors. When sleep disturbances exist, it is important that the treatment team understand, and efforts should be made to help treat the sleep disturbance. It is anticipated that improved sleep quality could result in reduced anxiety, less depression, and improved quality-of-life.



Dr. Nilsen, with her “blue ribbon” poster. She is co-founder of the Head and Neck Cancer Survivorship Clinic at UPMC. This clinic is unique in the world because it provides multidisciplinary care and allows Survivors to be evaluated in a single visit with a single copayment. The clinic also serves to provide the profession with new and important insight into the side effects of cancer treatment. Dr. Nilsen has been a leader in reporting these findings to the profession.

A Dietitian’s role in head and neck cancer

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Figuring this out can seem tedious and get frustrating, not only for the patient but also for the family. Food and eating is usually a pleasurable experience, but during treatment it can be very difficult and uncomfortable. A dietitian can review appropriate food and beverage options that provide adequate calories and protein without worsening symptoms; if anything, the dietitian will help alleviate symptoms with the recommendations provided. A dietitian may even recommend oral supplemental drinks such as Ensure, Boost, Carnation Instant Breakfast, and Orgain for additional calories and protein. Protein powders and other supplemental options may be used to maintain good nutrition.

A dietitian can discuss these options and even provide

samples to the patient to see what works well for them. The dietitian takes all aspects of care into consideration and makes recommendations accordingly to determine what is best for the patient.

If symptoms are so severe that a patient can no longer consume adequate nutrition orally, a feeding tube may be placed to supplement the diet. A dietitian will also manage the patient’s feeding tube (the formula, rate of administration and the correct regimen for adequate nutrition). A patient can continue to eat orally even with a feeding tube, if approved by the doctor and there is no risk for aspiration. Feeding tubes are typically temporary and really help patients who struggle to meet the needs from oral intake alone during treatment. Once treatment is complete and

symptoms improve, a dietitian can work with the patient to help wean off the tube feedings and increase oral intake to promote optimal nutrition.

Overall, maintaining a proper diet and receiving adequate nutrition is key before, during and after treatment. Good nutrition promotes health and may reduce the risk of disease recurrence. A well-balanced diet can still be achieved despite multiple side effects from treatment and a dietitian can help provide nutrition recommendations to do so. The dietitian will make sure patients meet their goals, ease symptoms and side effects, and improve quality of life through nutrition. To meet with a dietitian through the Hillman Cancer Center, contact 412-623-3325 or 412-864-7500.

One size doesn't fit all

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My concept is that there is something personalized about their disease that makes them different from the others. There's something about that particular patient who couldn't be saved that we want to study through genetics," says Dr. Duvvuri.

Dr. Duvvuri proposes to understand this by doing genomic sequencing of a cancer from a non-survivor, which may provide some clues as to the differences in the person's genetic predisposition to recurring, incurable cancer. Dr. Duvvuri recently performed a study, in conjunction with the Fred Hutchinson Cancer Research Center in Seattle, identifying a cohort of 20 patients with early stage HPV-positive oropharyngeal cancer who were treated and cured, and 7 who were treated and were not cured. When the cancer in these 7 patients recurred, we were able to biopsy both the original and recurrent cancers and compare them to those who were cured.

This type of 'before-and-after' study has not been done widely before, and can provide very useful information, perhaps patterns or even a 'signature' of incurable cancer. This information can be used to either escalate or deescalate treatments based on a patient's genetic information, resulting in better outcomes and greater chance for survival. While this study has provided many useful conclusions, the reality is that a study of 27 individuals is very small. There is a need to do more work in this area, with a larger number of participants to really identify what genetic components make someone a 'curable' or 'incurable' head and neck cancer patient. In addition to this project, Dr. Duvvuri is working to perform bioinformatic analysis with colleagues from the University of Washington-Seattle as well as the University of Pittsburgh Cancer Institute (UPCI), working closely with its Director, Dr. Robert Ferris, to do more analysis of this type, but funding is needed to continue working with other institutions to collect data from patients around the country.

Dr. Duvvuri states that, "while the goals seem lofty, they are within reach. The promise of personalized medicine is for patients to have the right treatment, for the right problem, at the right time. It's a simple idea, but difficult to accomplish."

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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.

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

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