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Survivorship Begins at Diagnosis

The Head and Neck Cancer Survivorship Clinic: A New Model of Multidisciplinary Care

Head and neck cancers (HNC) constitute the sixth leading cause of cancer worldwide, and there are approximately 60,000 new cases diagnosed annually in the United States. The majority of new cases are diagnosed as late-stage disease and typically have been associated with older adults — over the age of 50. However, with the rising rate of human papilloma virus-caused HNC, the overall trends are leading to an increase in cases and more cases diagnosed in younger individuals.



The burdens of these cancers for afflicted patients are significant, from diagnosis through treatment, to post-treatment survivorship. The physical, emotional, psychological, and financial implications of a diagnosis of head and neck cancer tend to be overwhelming for many, and they persist long after the diagnosis and initial therapies have been provided.

Jonas Johnson, MD, chair of the Department of Otolaryngology at the University of Pittsburgh, has devoted his career to the care of patients with head and neck cancer, and to research to improve outcomes and quality of life, and to reduce disease burden. “There’s an epidemic, silent as it is, of oropharyngeal cancers in this country as a consequence of the human papillomavirus. It’s one of only five types of cancer with increasing rates of incidence, and it is why we are seeing much younger ages with these diseases,” says Dr. Johnson.



Dr. Johnson has seen all too often the effects these diseases and their treatments have on patients. His desire to deliver a better, more patient-centric approach to managing the comprehensive effects and needs of head and neck cancer survivors led to his collaboration with **Marci Nilsen, PhD, RN**, a researcher in the University of Pittsburgh School of Nursing, to create a dedicated, multidisciplinary, comprehensive clinic that could manage and follow these patients over the long-term, addressing their unique needs and challenges as survivors.

Origins of the Survivorship Clinic

Officially launched in December 2016 after four intense and fast-paced months of planning, approvals, and work to obtain the necessary staffing, the UPMC Head and Neck Cancer Survivorship Clinic had its origins in prior work and discussions between Dr. Johnson and Dr. Nilsen while she was working on a postdoctoral research project studying patients who had lost the ability to

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Recent Advances in Skull Base Surgery

The UPMC Departments of Otolaryngology and Neurological Surgery have been pioneering developers and proponents of the endoscopic endonasal approach (EEA) to skull base surgery for more than 30 years. In that time, the faculty and the skull base surgery program have become internationally sought for their surgical skills, research, and educational programs designed to teach aspects of EEA to new generations of surgeons around the world.



“What is unique about the UPMC staging system for angiofibromas is its consideration of the blood supply to the tumor, not just how large the tumor is or where it is located.”

Carl Snyderman, MD, MBA

Carl Snyderman, MD, MBA, professor in the Department of Otolaryngology, with a secondary appointment as professor in the Department of Neurological Surgery, has been with UPMC and the University of Pittsburgh since completing his residency in Otolaryngology in 1987. Dr. Snyderman and Paul Gardner, MD (associate professor in the Department of Neurological Surgery), are co-directors of the UPMC Center for Skull Base Surgery, the first of its kind in North America. Dr. Snyderman was the first fellow to complete the cranial base surgery fellowship in 1989. Since then, Dr. Snyderman has been at the forefront of cranial base surgery, exploring new applications of the endoscopic endonasal approach, and driving advances in research and education. Dr. Snyderman is a past president (2015) of the North American Skull Base Society (NASBS) and is a current member of its board of advisors.

The last several years have seen the advent of new technological advances, new surgical procedures, and new training programs from Dr. Snyderman and his colleagues, continuing the mission and expanding the legacy of Pittsburgh as a pioneer and leader in skull base surgery across the world.

Technological Achievements

Presented in abstract form during the scientific and poster sessions of the 2018 NASBS meeting, the UPMC Skull Base Team described the use of the fluorescent dye, Indocyanine Green (ICG), during endoscopic skull base surgery.¹ ICG is injected at the time of surgery. As the dye permeates the tissues and blood vessels, the fluorescent properties of the dye, visualized through a special type of endoscope, allow the surgeons to see the blood vessels in question. “The dye gives us a better ability to assess the vascularity of tumors and other tissues during surgery,” says Dr. Snyderman.

Dr. Snyderman explains that the technique is still somewhat investigative, but he and his collaborators are actively researching its applications and use in various skull base surgical approaches. “ICG is FDA-approved for some use, but applications of this modality for EEA with use of a special fluorescent endoscope to visualize the tissues is quite new. We’re excited about the potential prospects for this new technique in differentiating tumors from normal tissues,” says Dr. Snyderman. “We have already demonstrated its value in assessing the viability of vascularized reconstructive flaps.”

New Surgical Technique: The Contralateral Transmaxillary Approach

Published in the *Journal of Neurosurgery* in October 2017, Dr. Snyderman and colleagues outline a new surgical technique they have developed called the *contralateral transmaxillary approach* (CTM).²

The CTM approach allows surgeons to access the difficult-to-reach region of the petrous apex with an improved angle of approach of approximately 25 degrees, versus what would normally be required through an endoscopic endonasal approach.

“This region of the skull base is a very challenging area to access; removing large tumors from it with other techniques is difficult and dangerous. CTM allows us to access this region by coming at it from the opposite side via the sinuses. This approach allows us to work behind the carotid artery, greatly diminishing the risk inherent with that area,” says Dr. Snyderman.

Their study and characterization of the technique, performed on a cadaveric model, compared the CTM approach against the standard EEA for accessing this region.

Clinical experience suggests that there may be a reduction in risk and morbidity with the approach because of the improved lateral trajectory of access to the petrous apex and avoidance of the paraclival segment of the internal carotid artery.

The first group of researchers to describe this procedure and publish on it in a medical journal, Dr. Snyderman and colleagues also presented on the topic during the most recent NASBS meeting with poster,³ and oral presentations.^{4,5}

New Research: Lumbar Drains — To Use or Not Use

One of the current unresolved issues in skull base surgery is whether surgeons ought to use lumbar drains to draw off cerebral spinal fluid (CSF) in order to reduce CSF pressure. “These devices are often placed after surgery to aid in the healing process. When to use them lacks consensus among surgeons. No one had ever done a randomized trial to prove when or under what circumstances they should be used,” explains Dr. Snyderman.

That is until recently, when the UPMC skull base team designed and conducted the first randomized trial of lumbar drains in endoscopic skull base surgery. Results of this study, which clarify when it is appropriate to use lumbar drains, are in the midst of publication.

“Upon completion of our randomized trial, we initiated a follow-up study⁶ to assess the cost-effectiveness of the use of lumbar drains,” says Dr. Snyderman. These results also were presented in February at the NASBS and confirm the value of CSF drainage in selected patient groups. The full abstract of the study is available for viewing at the NASBS meeting website.

Staging System for Angiofibromas

In 2010, Dr. Snyderman and colleagues published their work on the development of a new staging system for juvenile nasopharyngeal angiofibroma,⁷ benign tumors that largely occur in adolescent males. Angiofibromas are slow growing but carry a high risk of intraoperative bleeding and need for additional surgeries. This retrospective study examined surgical cases from 1998 to 2008, and compared a new staging system against the current systems at the time. The UPMC staging system developed by Dr. Snyderman accounts for two important prognostic factors: the route of cranial base extension and tumor vascularity. The UPMC staging system was shown, in comparison, to provide a more accurate prediction of morbidity and tumor recurrence.

Since that initial publication in 2010, Dr. Snyderman has continued to study the UPMC staging system and advocate for its wider adoption. “What is unique

about the UPMC system is its consideration of the blood supply to the tumor, not just how large the tumor is or where it is located,” says Dr. Snyderman.

Most recently, Dr. Snyderman and colleagues have published a second retrospective study on surgical cases of angiofibroma at UPMC from 2008 to 2015.⁸ The findings from this study looked at outcomes related to intraoperative blood loss and transfusions, number of staged operations, postoperative residual disease, and recurrent disease. Results from this study again showed that the UPMC staging system was a better predictive model in determining patients who required staged procedures, received intraoperative transfusions, and had residual postoperative disease.

Dr. Snyderman is collaborating with international sites to further validate the UPMC staging system and presented recent findings at the 2018 NASBS meeting.

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Members of the Center for Skull Base Surgery — Left to Right: Paul Gardner, MD; Elizabeth Tyler-Kabara, MD, PhD; Juan Carlos Fernandez-Miranda, MD; Carl H. Snyderman, MD, MBA; Eric Wang, MD.

Approaches to Learning Skull Base Surgery

Training surgeons to perform endoscopic skull base surgery is a hallmark of the Center for Skull Base Surgery, with Dr. Snyderman and colleagues performing and pioneering many training initiatives, symposia, and conferences for surgeons in the United States and globally. This work continues to expand, and so too does the research into training and educational techniques. "In 2010, we published an article that described how surgeons should approach the learning of endoscopic skull base surgery, and we established a five-level training program," says Dr. Snyderman. The training is a scaled program, moving from simple to more complex surgeries and a progression in training on the learning curve. Recently, at the 2018 NASBS, Dr. Snyderman and colleagues presented research from two years of cases and categorized them according to the training levels of the program. This research was able to validate the training levels and how they correlated with patient outcomes and risks.

Safety of Live Surgeries

Another recent research project, likely the first of its kind, was a study examining the safety of live surgical procedures for educational courses. "Systematically, there is very little research on the subject. However, there are concerns about whether it is ethical to televise a live surgery for an educational course. We recently analyzed our experience with the televised, live surgical courses we have been doing since 2005 and showed that there really are no serious events, and the outcomes were on par with and sometimes better than non-televised procedures. We presented some of these findings at NASBS 2018 and are now reviewing our experience with live international surgeries," says Dr. Snyderman. "We have shown that live demonstration surgeries can be performed safely as long as surgeons adhere to certain principles and are aware of the risks."

Decision Making Tools for Complex Medical Problems

In collaboration with a local Pittsburgh software company, Dr. Snyderman is working to develop a decision-making tool for patients with complex medical problems. "The first one that we are addressing is the choice of therapy for acoustic neuromas," says Dr. Snyderman. Acoustic neuromas are benign tumors that affect hearing. The decision-making tool, an online application, will help patients choose between observation, surgery, or radiation therapy.

"Longer term, I think this tool will be applicable to a wide range of medical problems, and it affords a way of incorporating the values of the patient into the decision-making process. It is really a shared decision-making model that more effectively incorporates the patient's goals and values into the equation."

An Ever-Expanding Desire to Improve

Dr. Snyderman's work with skull base surgery — its procedural complexities, training, research, and development of novel tools and platforms for both surgeons and patients — will continue. New to his portfolio of projects, and new in general, is a project working with a popular "brain-training" company to determine whether, through an analysis of testing results through the platform, predictions can be made as to which surgeons are likely to be better at surgery. These studies are just entering trial phase and will be ongoing for approximately the next 12 months. "If the results are positive, we can then look for ways to improve surgical performance through brain-training exercises."

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of Otolaryngology, University of Pittsburgh School of Medicine; ³Department of Neurological Surgery, University of Pittsburgh School of Medicine.

- ² Patel CR, Wang EW, Fernandez-Miranda JC, Gardner PA, Snyderman CH. Contralateral Transmaxillary Corridor: An Augmented Endoscopic Approach to the Petrous Apex. *J Neurosurg*. 2017; 20: 1-9. Epub ahead of print.
- ³ Poster Presentation at the 2018 North American Skull Base Society Annual Meeting: P012: Contralateral Transmaxillary Approach Vs. Purely Transnasal Approach to the Petroclival Region: An Anatomical and Radiological Study. Joao Mangussi-Gomes, MD¹, Gustavo F Nogueira, MD², Eric W Wang, MD³, Juan C Fernandez-Miranda, MD⁴, Carl H Snyderman, MD, MBA³, Paul A Gardner, MD⁴. ¹Surgical Neuroanatomy Lab, UPMC Center for Cranial Base Surgery; ²Neurological Institute of Curitiba; ³Department of Otolaryngology, University of Pittsburgh School of Medicine; ⁴Department of Neurological Surgery, University of Pittsburgh School of Medicine.
- ⁴ Poster Presentation at the 2018 North American Skull Base Society Annual Meeting: P111: Utilization of the Contralateral Transmaxillary Approach for Chordoma and Chondrosarcoma of the Petrous Apex. Daniel L Faden, MD, Philippe F Lavigne, MD, Juan C Fernandez-Miranda, MD, Paul A Gardner, MD, Eric W Wang, MD, Carl H Snyderman, MD, MBA. UPMC.
- ⁵ Scientific Session of the 2018 North American Skull Base Society Annual Meeting. 068: Contralateral Transmaxillary Corridor: Surgical Planning and Pathway Analytics. Rajeev Sen, MD¹, Rajeev C. Saxena, MD, MBA¹, Nava Aghdasi, PhD¹, Yangming Li, PhD¹, Randall Bly, MD¹, Paul Gardner, MD², Carl Snyderman, MD², Kris S Moe, MD¹; ¹University of Washington; ²University of Pittsburgh.
- ⁶ Scientific Session of the 2018 North American Skull Base Society Annual Meeting. 202: Lumbar Drainage May Represent a Cost Saving Method for Skull Base Surgeries. Vishal Patel, BA¹, Gurpreet Gadhoke, MD², Paul A. Gardner, MD³, Carl H. Snyderman, MD, MBA³; ¹University of Pittsburgh School of Medicine; ²Department of Neurological Surgery, University of Pittsburgh School of Medicine; ³UPMC Center for Cranial Base Surgery.
- ⁷ Snyderman CH, Pant H, Carrau RL, Gardner PA. A New Endoscopic Staging System for Angiofibromas. *Arch Otolaryngol Head Neck Surg*. 2010; 136(6): 588-594.
- ⁸ Rowan NR, Zwagerman NT, Heft-Neal ME, Gardner PA, Snyderman CH. Juvenile Nasal Angiofibromas: A Comparison of Modern Staging Systems in an Endoscopic Era. *J Neurol Surg B Skull Base*. 2017; 78(1): 63-67.

Head and Neck Cancer Survivorship Begins at Diagnosis *Continued from Page 1*

communicate with their care providers while in the hospital. Many of these cases were survivors of head and neck cancer dealing with significant side effects, which sometimes is the loss of their voice. "During the course of her research," says Dr. Johnson, "she and I began to talk more and more about the suffering that we were observing in our cancer survivors. And at the same time, she was discussing the growing movement in survivorship care for cancer patients, in addition to the Institute of Medicine's recommendations on fundamental services for these patients."

These discussions culminated in August 2016 with the desire from Dr. Johnson to approach the care of these patients in a different manner. Thus began the complex process to plan, build, and launch a multidisciplinary clinic for head and neck cancer survivors.

In the Clinic: Multidisciplinary Management

At present, the clinic operates one day a week, seeing patients in various stages of their survivorship, be it pre-, during, or post-treatment. However, a significant portion of the clinic's work goes on in between the weekly sessions — arranging follow-up appointments, planning for new cases, discussing current cases or changes in a patient's status, and much more.

The clinic consists of Drs. Johnson and Nilsen, along with an audiologist, speech language pathologist, physical therapist, swallowing therapist, and dentist. Patients are able to see all of these clinicians for the care and follow-up they need with a single co-payment, reducing the financial burden and streamlining the follow-up process into a single, multiprovider visit.

For Drs. Johnson and Nilsen, and the clinic staff, the philosophy is that survivorship begins at the time of diagnosis. While the clinic was focused on post-treatment

patients during the initial months of operation in early 2017, inquiries and referrals from colleagues across UPMC pointed to a need to address and see some patients before they started their cancer therapy. Now, the clinic routinely sees patients in all stages of their disease. "It's not uncommon for us to be evaluating and discussing care with a patient who has recently been diagnosed, and we also see patients who are long-term survivors, some of whom are 30- and 40-years post-treatment," says Dr. Nilsen. This is a testament to some of the progress made in curing these individuals, but it is also a heartbreaking revelation that even after such a duration cancer-free, these individuals are still facing challenges. "These cases are confirmation that this kind of care for head and neck cancer survivors is relevant, and badly needed," says Dr. Johnson.

One unique aspect of the clinic is that all patients respond to a patient-reported outcome questionnaire that is reviewed and responded to in real time during the visit. "We designed this aspect such that the questions we pose are ones we can act upon immediately. We use the University of Washington Quality of Life measure because it allows patients to prioritize their issues and identify which ones they have been affected by in the last seven days.

Before I go in the room to talk to the patient, I already know what they are struggling with and can concentrate on those aspects," says Dr. Nilsen. The clinic also screens for issues related to depression and anxiety, swallowing issues, oral health, neck disability, and health literacy. Clinicians will typically address first whatever the patient is having the most difficulty with and home in on the specifics. These measures are tracked longitudinally in the patient's EHR so progress can be assessed over time and the data can be mined in the future for research initiatives.

During the clinic planning process, it was determined that the EHR for the clinic and the treatment summary needed to be a dynamic process. Patient records include pertinent information, such as tumor and surgery details and other past treatment notes. Additionally, each of the providers who see the patient in the clinic can, and do, write a note to the patient. These notes outline such things as the exercises they were given to perform, notations about any limited range of motion or pain, and what to do if they have questions. "We arm them with as much information as possible, and Dr. Johnson outlines when they should return for follow-up. The audiologists provide them with information about their screening. If the patient didn't want to get an audiogram that day, we give them

instructions on where they can go to have a full audiogram done at a more convenient time. The same applies to any notes from PT, dentistry, and the other providers in the clinic. At every visit, the patient gets a detailed, personalized note summarizing everything that happened in clinic and what the follow-up steps are," says Dr. Nilsen.

Since the clinic opened in December 2016, approximately 550 unique patients have been seen, and that number continues to increase as knowledge of the clinic's existence grows and the referral base expands.



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Head and Neck Cancer Survivorship Begins at Diagnosis *Continued from Page 5*

Learnings, Challenges, and Changes Along the Way

Drs. Nilsen and Johnson learned much during the first months of the clinic's operation, and they worked to adapt, change, and add new features as they learn more about the specific patient populations they are treating, and consequently, their specific needs.

For example, through screening and data capture, Drs. Nilsen and Johnson have determined that approximately 17 percent of the clinic's patients have an inadequate level of health literacy. "This has shown us that we have to be very careful with not only the information we hand out, but in how we present the information during discussions so the patients are able to understand, process, and act upon what they are being asked to do. No one is served well if, when a patient leaves our clinic, they are thoroughly confused. This is a complex challenge we are addressing in multiple ways, for example, systematically reviewing and revising our existing patient materials," says Dr. Johnson.

The clinic also is working to add an additional staff member, a geriatrician with expertise in both internal medicine and behavioral health, who will be able to help coordinate care for individuals with either of these needs as part of their overall care. For older adults, polypharmacy can be a significant issue — when medications for age-related health issues are added on top of the medications they need for aspects of their cancer — and a geriatrician is well-positioned to be able to help manage the complex needs of the older adult.

Research and Future Plans

With their ability to gather precise data on clinic patients longitudinally through the EHR and appended with various survey instruments, Drs. Nilsen and Johnson and their collaborators have an exciting portfolio of research projects either in progress or in development — 10 individual projects at the time of writing, all conceived and started within the relatively short 16 months the clinic has officially been in operation treating patients.

One current project seeks to better understand the nature and implications

Clinic Staff

Jonas Johnson, MD

Marci Nilsen, PhD, RN (*Nurse*)

Debra Pickford, BSN, RN (*Nurse*)

Tami Wasserman-Wincko, MS,
CCC-SLP (*Speech Language Pathologist*)

Susan George, PT, DPT, MS
(*Physical Therapist*)

Antonia Teruel, DMD, MS, PhD
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Elizabeth Dervin (*Audiology Assistant*)

Jatta Bluefort (*Medical Assistant*)

Maria Panian (*Scheduler*)

Patricia Kemerer (*Practice Manager*)

of treatment-associated financial toxicity. Treatments are expensive; ongoing therapies such as physical and speech therapy, medications, and other care needs can extend far into the future as more and more patients survive longer and longer. Head and neck cancer patients have very specific late- and long-term effects requiring management. Drs. Johnson and Nilsen's research hopes to better understand what the financial burdens facing these patients truly look like and how these may affect whether, when, and to what degree they are compliant with the prescribed or recommended care plans. "As providers, we have to do a better job of identifying when a patient is not compliant, what the barriers and reasons for it are, and whether we can help mitigate it so they can receive the treatment they need," says Dr. Nilsen.

Other in-progress lines of research are examining aspects of neck dysfunction. There is a growing understanding and concern that cognition can be impaired or affected by treatment therapies. There is some evidence in the literature that significant percentages of patients experience some form or degree of cognitive impairment after treatment, so Drs. Johnson and Nilsen are beginning to examine better ways to screen for or assess issues related to cognition in their clinic patients.

"At the same time, we are interested in understanding which stretching and exercises are most effective in caring for people with stiff neck and shoulders. We are interested

in which interventions work best for people experiencing dysphagia and a host of other common complications. These kinds of side effects to treatment are far more prevalent than anybody has ever acknowledged. The next question, of course, is do these side effects get better with time? Unfortunately, what we are finding is they actually tend to get worse. Can we dampen or reduce the trajectory of these side effects? Our current hypothesis is the old adage: use it or lose it. So, we are learning that we must address these complications right at the time of treatment and then stay on top of it. These are the research questions for which we seek answers, and the design of our clinic will allow us to gather the longitudinal information needed to develop the next-generation of standards of care for head and neck cancer survivors," says Dr. Johnson.

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Save the Date: Inaugural Survivorship Symposium — August 6-7, 2018

An extension of the UPMC Head and Neck Cancer Survivorship Clinic's trailblazing work in patient care is the development and inaugural presentation of the Head and Neck Cancer Survivorship Symposium.

This multidisciplinary, one-day event brings together clinicians and researchers from the fields of medical, surgical, and radiation oncology, as well as the allied health providers that are part of the UPMC Head and Neck Cancer Survivorship Clinic — nursing,

dental medicine, physical medicine and rehabilitation, and physical therapy.

The objective of the symposium is to discuss and provide the fundamentals necessary for an effective and multidisciplinary approach to survivorship care for the head and neck cancer patient.

This symposium also integrates patients who provide firsthand perspectives on navigating the care process and what it means to be a survivor of head and neck cancer.

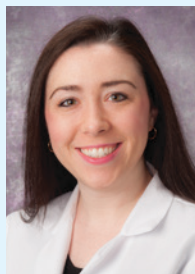
Specialists, primary care providers, nurses, residents, audiologists, speech language pathologists, physical therapists, dentists, and other interested disciplines are encouraged to attend.

For additional details including registration information and presenting faculty members, please visit Otolaryngology.Pitt.Edu/Event/2018-Survivorship-symposium.

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An Overview of Tinnitus Research

Lori Zitelli, AuD, gives a presentation on tinnitus, its common characteristics, and the current standards of treatment. Dr. Zitelli also discusses the current state of evidence-based research into the condition, and how these findings are difficult to generalize and apply to treat this heterogeneous condition.



Endoscopic Endonasal Intracranial Surgery: Update

In this presentation, **Eric Wang, MD**, reviews the advantages of intracranial surgery via the endoscopic endonasal approach (EEA) with a specific focus on increased preservation of pituitary function. Dr. Wang's course reviews the relevant anatomy of the anterior skull base necessary for a transcribriform resection of a sinonasal tumor and other aspects of the EEA to skull base surgery.

Video Rounds



Researching a Viable Treatment for Tinnitus

Presented by:
Thanos Tzounopoulos, PhD

Dr. Tzounopoulos discusses his search for a treatment for tinnitus, in addition to his cellular and molecular studies elucidating the basic biology and mechanisms for the causes and maintenance of the condition.



Update in Robotic ENT Surgery

Presented by:
Umamaheswar Duvvuri, MD, PhD

Dr. Duvvuri discusses recent advances in robotic surgery for ENT patients at UPMC.



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The department has more than 40 full-time faculty members, representing all the subspecialties of otolaryngology. While the primary mission continues to be providing high-quality patient care, we also are dedicated to advancing education and research within the field of otolaryngology.

To learn more about the UPMC Department of Otolaryngology, please visit UPMCPhysicianResources.com/ENT.

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