

HEADWAY

SINCE 2007

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

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Jonas T. Johnson, MD: a surgeon, a clinician, a teacher, and a leader

By Lisa A. Goldstein

After 42 years at the University of Pittsburgh, 16 of which were as Chairman of the Department of Otolaryngology, Dr. Jonas T. Johnson is stepping down. But make no mistake, he's not retiring. If anything, he's reinventing himself.

As much as he has loved being in the operating room, where he has helped patients and trained the next generation of physicians, Dr. Johnson felt an obligation to step down.

Once his successor is named, Dr. Johnson plans to focus on helping run the UPMC Head & Neck Cancer Survivorship Clinic, where he hopes to raise awareness and understanding about survivorship among his colleagues and treat patient side effects more effectively.

"Dr. Johnson would not necessarily say this, but his legacy will certainly be his patients, who have expressed directly to us at the Foundation their admiration and appreciation for him," says Eye & Ear Foundation CEO Lawton Snyder. "He connects with them directly, and they appreciate him for those human qualities."

Snyder also cites the many physicians Dr. Johnson has trained over the years, as well as his and the Department's numerous accomplishments as part of his "incredible legacy." He truly exemplifies what a chairman can and needs to do, he adds.

That legacy includes a career spent on the care of people with head and neck tumors, a rank of Distinguished Service Professor at the University of Pittsburgh School of Medicine, and joint appointments in the Department of Radiation Oncology, Department of Oral and Maxillofacial Surgery at the University of Pittsburgh School of Dental Medicine and Department of Communication Science and Disorders in the School of Health and Rehabilitative Sciences. Dr. Johnson is also a Past President of the American Academy of Otolaryngology Head and Neck Surgery (2003), the American Head and Neck Society (2004), and the Triologic Society (2014).

"What I truly enjoyed was being able to practice medicine in this environment of research and education," says Dr. Johnson.

Near and dear to his heart is the Survivorship Clinic, initiated when he was approached in 2015 by Dr. Marci Nielsen, a postdoctoral candidate at the time. She asked if she could join him in the Clinic to recruit patients for a research project. Through this,



Lawton Snyder and Jonas T. Johnson, MD.

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God is with us

By Lisa Barcus Vulakovich
Cancer Survivor



Lisa Barcus Vulakovich with her husband, Tom.

On July 7, 2021 my entire life changed when my gynecologist, Dr. Maureen Russell, informed me that I had a rare and aggressive cancer, Carcinosarcoma of the Endometrium. I was told I would be scheduled immediately for a complete hysterectomy as soon as possible only to find out two weeks later that not only did I have Carcinosarcoma but also Adenocarcinoma. My left Fallopian tube showed to be precancerous for Fallopian cancer and I would need an additional surgery in four weeks. Thankfully, the Fallopian cancer did not spread and the surgeon believed she removed all of the cancers. I still needed to complete six rounds of chemotherapy and four internal radiation treatments, but God was with me through it all.

Since that day, my life has been blessed with so many Godwinks or signs. The first one was when a co-worker/friend, Jen Matelan, unbeknownst to me, sent my name to the Mrs. Claus Club. My head was still reeling from the news of cancer when the care box arrived. I opened it and immediately began crying. I really didn't know very much about The Mrs. Claus Club and I couldn't imagine who could have cared that much to send me this box. Inside the box was a card from Jeana Watenpoole, President of The Mrs. Claus Club. I called her and she told me that it was my friend Jen who requested that a box be sent to me. Talking with Jeana was the first connection with someone who understood what I would be going through. That box and the conversation with Jeana made me feel loved and that I was not alone.

The next Godwink happened when I had my first appointment at West Penn's Cancer Center. I was very anxious so I was talking to God in my head. This man walked across the waiting room straight to me and said, "God told me to tell you that everything will be okay." I burst into tears. I now call him Angel Bob and talk or text him several times a week about our faith and encouraging other people.

The last and most profound Godwink was when I was having my first radiation appointment. They asked what type of music I wanted to listen to and I said Christian. I was laying on the table, the physicist used the Geiger counter to wand me and then he left the room. I thought to myself, "I am all alone in here." This song that I had never heard before began to play. In the middle of the song, the artist stops singing and tells the band to continue to play. Then the artist says, "God is in this room right now! Put your hands up. God is here right now. He is in the midst of our pain and struggles right now! You are not alone, you are not alone, you are not alone!" It took every ounce of energy for me to not move or cry. When the radiation team came back in, they asked me how did I do? I told them that after hearing that song I felt great! Once I was in my car, I Googled the song – it was the live version of Justin Bieber's "Purpose."

No matter what we are struggling with right now we need to remember that first, we are not alone. We need to share our trials with each other, asking for prayer. Second, God is going to see us through whatever is happening, we just need to open our hearts and trust him. And third, God doesn't give us more than we can handle. He has a purpose for each of us and it is up to us to make something of our lives.

Quality-of-life in recurrent and second primary head and neck cancer

By Vaibhav Ramprasad, MD
Resident Physician



Head and neck squamous cell carcinoma (HNSCC) accounts for approximately 4% of all cancers diagnosed in the United States.

Overall, survival has been gradually improving over the last three decades, from 55% in 1992-1996 to 66% in 2002-2006. This has been, in large part, due to advances in utilizing multiple types of treatments to treat cancer. Currently, surgery, chemotherapy and radiation therapy are all used, either individually or in combination to treat HNSCC. Unfortunately, the use of these therapies is not benign and can have associated side effects. Due to the importance of the head and neck in communication and swallowing, side effects of treatment can have profound adverse effects on these very basic human functions.

With the increase in rate of cure of HNSCC over the last few decades, we have turned our attention to caring for patients with toxicities from prior cancer therapy, even if they have been completely cured. Approximately 50% of all patients who undergo treatment for head and neck cancer with radiation therapy experience impairment with swallowing and speech. Dysphagia, or trouble swallowing, is present in up to 45% of patients diagnosed with HNSCC even two years after having had oncologic treatment.

A multi-disciplinary approach is increasingly being utilized in rehabilitating HNSCC survivors after treatment in the form of survivorship clinic. This allows for providers from a range of disciplines including speech language pathology, physical therapy, dietetics, dental medicine, and audiology to participate in the care of patients with treatment-related disabilities. Furthermore, a longitudinal survivorship clinic allows providers to monitor health-related quality of life (HRQOL) over time



For additional topics on the prevention, detection and treatment of cancer, including head and neck cancer, visit www.hillmanresearch.upmc.edu

www.hillmanresearch.upmc.edu/about/news/publications/archived-issues-of-headway

in patients. Standardized questionnaires administered at each visit allow for the collection of Patient Reported Objective Measures (PROM), which provide objective metrics to track effect of treatment on quality of life. The eventual goal of utilizing PROMs to measure HRQOL is to allow providers, and more importantly, patients, to be able to make informed decisions about treatment based on the effect on quality of life.

Our study, performed in conjunction with Dr. Marci Nilsen and Dr. Jonas Johnson, looked at outcomes in patients with recurrent (cancer that is initially cured which returns after completion of treatment) and second primary (separate tumor that arises in a location discrete from initial cancer). When people require additional treatment, very few studies have looked at associated changes in patients undergoing additional treatment for these types of cancer. Our results show that people with recurrent or second cancers develop more challenges. Understanding these data help providers better support the patients and their families.

Head and neck cancer survivorship: What does tinnitus have to do with it?

By Rahilla Tarfa, Ph.D.
4th Year Medical Student, The University of Pittsburgh School of Medicine



The race for the cure of head and neck cancer remains challenging. While therapeutic advancements are currently under active investigation,

head and neck cancer surgeons remain committed to improving the quality of life of head and neck cancer survivors. Access to multidisciplinary care remains one of the best ways we can provide effective care to help survivors return to an optimal quality of life and regain a sense of control. One of the challenging aspects of head and neck cancer survivorship is ensuring survivors maintain the ability to communicate. An aspect of communication that has not been widely examined in head and neck surgery survivorship literature is hearing and tinnitus. This is especially important as some forms of treatment for head and

neck cancer, including chemotherapy and radiation, can affect hearing. As such, it is necessary to know which head and neck survivors need hearing augmentation as they progress through different treatment regimens. Additionally, the psychosocial needs of survivors who have hearing impairment in the form of hearing loss, and/or tinnitus, may be different from survivors without this impairment. Our research group has taken up the mantle to explore how hearing impairment is associated with psychological distress and quality of life among our patients in the Head & Neck Cancer Survivorship Clinic. It is our hope and goal that by identifying these associations, we can provide better tools in the form of interventional therapies that can help survivors cope with their hearing impairment as they advance through head and neck cancer treatment and survivorship.

Our study looked at survivors, between 2016-2020, who were first-time patients in the clinic following their first treatment for head and neck cancer. First, we looked at the fraction of our patients who have some form of hearing impairment measured as either hearing loss in one or both ears, and tinnitus. We found that about 75% of our survivors have some hearing loss and roughly 40% of our survivors have tinnitus. We wanted to understand if survivors with hearing loss or tinnitus were more likely to report a worse quality of life or higher score on the depression (PHQ-9) or anxiety (GAD-7) scales. We found that survivors with hearing loss did not have worse quality of life, anxiety, or depression. However, our data showed that survivors with tinnitus were associated with having worse quality of life. In particular, these survivors scored higher in what we term the social-emotional sub-scale in the University of Washington quality of life questionnaire, which measures anxiety, mood, pain, and activity, to name a few. Additionally, these same group of survivors scored higher on the depression and anxiety scales.

Our results show that head and neck cancer survivors with tinnitus are associated with worse quality of life, and higher scores on the depression and anxiety scales. These results identify a vulnerable sub-group of survivors in which intervention measures, tailored towards mitigating their symptoms to improve their quality of life and

survivorship experience, can go a long way. While there is no cure for tinnitus, the presence of this confounding ailment could worsen the survivorship experience especially if symptoms are severe or bothersome. Collaboration within our multidisciplinary team, working with audiologists and otologists, could bring about clinical solutions that can be implemented for these patients. Current therapies that could be recommended to these survivors to improve tinnitus symptoms include cognitive behavioral therapy, traditional counseling, and sound therapy, and could be offered as a trial to improve their quality of life. While we do not know if these patients are at an increased risk of worsened tinnitus with current head and neck cancer treatments, our work presents the opportunity for more questions to be asked in this arena. Our clinic's ability to continue to ask the questions that matter means we will continue to find solutions to improve the quality of life of our patients.

Cancer...me?

By Connie Knarr
Cancer survivor



Don and Connie Knarr.

My diagnosis of colon cancer came about in a sort of goofy way. When I had turned 50, my PCP mentioned that I should have a baseline colonoscopy. What? I told him that he needed to have a better reason than my age to have this test. Fast forward to one year later, and my husband's identical twin brother had a colonoscopy and polyps were found. This is where in my story that I realized that my Jesus stepped into the picture in a very unusual way. My husband refused to be tested, so I decided to make an appointment for myself to show him how easy a colonoscopy can be.

On the night before my colonoscopy, I had a vivid dream of the doctor telling me

that I had colon cancer. I had always thought that this form of cancer was hereditary and there had never been anyone in my family with this. My dream became a reality the next afternoon. My husband and I cried, and prayed, and cried again and again. We knew this was going to be a battle and that I needed prayers, so I called upon close friends which included Jeana, president of the Mrs. Claus Club in the Pittsburgh area. Jeana boldly told me that the Lord had given her a word for me...MIRACLE.

The next couple of weeks were a blur as several dates and times were set for scans, labs, daily radiation, and chemo in preparation for the needed surgery. Surgery and post op seemed to go amazingly well. After being discharged from the hospital, I experienced a few complications but knew the prayers were still being prayed.

I wanted and expected my kind of miracle. I begged and pleaded with God for a miraculous healing. I learned that a miracle isn't always an instant healing, or even a physical one. Yes, I had been physically healed by the Lord using so many wonderful people in the medical field. I can't say enough about the wonderful, compassionate care I received at UPMC Shadyside Hospital - inpatient, outpatient, cancer center, and so many other areas involved in my care. I prayed and had comfort in knowing that God guided the surgeon's hands; God instilled the knowledge and wisdom into the minds of all involved; God instilled the compassion into so many kind and wonderful individuals. He was with me in every way because He said in the bible, "I am with you always," Matthew 28:10. I also experienced miracles such as seeing my life in a different way. I noticed that things that used to bother me now just seemed trivial in the big scheme of life. I looked at people in a more compassionate way and became a more giving person. I was living out the saying "You never know when your time is up." This saying made me more aware of other people and their needs in life. Yes, I still don't know "when my time will be up," but I was, and still am, thanking God for this precious time I am given each day as a gift.

Back to the Mrs. Claus Club organization that I had mentioned earlier. Prior to my cancer diagnosis, I met the president Jeana at a bible study. We started a conversation and found out that we had

so many common interests. She told me about this organization. I remember thinking wow, that is a neat organization and great for her, but I was just so busy in my own life and didn't know how I could help. I never imagined that I would someday very soon be a recipient of a cancer comfort care basket from her. During her visit, I then realized that I, indeed, was to become part of this organization. I love to knit and started knitting prayer shawls and chemo hats to be given to others diagnosed with cancer. I believe this was also a miracle that God placed Jeana into my life, knowing that I would need her and her ministry.

I want to end my story with encouragement. I am now a 12-year, stage 3 colon cancer survivor. Yes, you may be experiencing terrible struggles, but keep fighting because every day, you are now a survivor, a mighty survivor.

Thank you for fighting.

A dietitian's role in head and neck cancer

By Alyssa Mrozek Weinfurther, MS, RD, CSO, LDN

Lead dietitian, Food and Nutrition Department, Hillman Cancer Center, part of UPMC Magee-Women's Hospital



A dietitian is an expert in the field of nutrition. We help our patients meet their nutrition needs throughout their cancer journey. Our role with head and neck cancer patients is very crucial to help keep them feeling strong throughout treatment and beyond. We help patients learn how to optimize their nutrition intake and maintain their weight in addition to managing side effects (like nausea, vomiting, chewing/swallowing difficulty, and taste changes). By providing educational resources individualized to each patient's needs, we help patients optimize their nutrition intake during treatment and achieve better outcomes after treatment.

One of the most important things we encourage our patients to do during treatment, especially if they have difficulty eating or decreased appetite, is to focus on increasing intake of calories and protein foods. By eating enough

calories and protein, patients can maintain weight and muscle mass. Choosing foods high in these areas or supplementing with high calorie/protein shakes can make a difference with treatment. There are many commercial products at the grocery stores and drug stores that can help supplement the diet. Some of the best known nutrition supplements are Ensure, Boost, and Premier Protein. While these products have their benefits, they can be costly if needed in larger amounts. Homemade high calorie/protein shakes can be just as beneficial. By combining ice cream, milk or yogurt, protein powder, and fruits/vegetables in a blender, a nutrition shake can be made at home.

Additionally, sometimes regular-consistency foods can be harder to eat if chewing and swallowing is more challenging based on location of the tumor, in addition to side effects from chemotherapy, radiation, or surgery. If this occurs, a dietitian may suggest choosing softer foods (requires little chewing) or more pureed foods (smooth and requires no chewing, like pudding). These foods tend to be easier to eat and can make eating less challenging or time consuming. Dietitians can work with Speech Language Pathologists to make recommendations for the most appropriate consistency for each patient. Sometimes these changes to the consistency of food are temporary, but sometimes it can be a more permanent strategy.

A common side effect of chemotherapy and radiation that can affect desire to eat is taste changes. These changes are different for every person, so our recommendations are individualized. Most commonly, foods tend to lack taste or taste different, bad, or like metal. There are different strategies, like using lemon candy prior to a meal, plastic utensils, or a water/salt/baking soda mouth rinse prior to meals, that can help improve some of these changes to taste. Radiation commonly causes dry mouth as well. Dry mouth can make chewing/swallowing difficult because often the saliva gets very thick. The thickness of the saliva can affect the texture of food in the mouth and make chewing or swallowing more difficult.

Dietitians can also help patients meet nutrition needs through a feeding tube. Patients who are unable to meet their calorie needs by eating can consider

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My journey through cancer

By Suzanne McCarthy
Cancer survivor



Dan and Sue McCarthy.

My journey through cancer goes back to early spring of 1980. I was twenty-eight years old and four months pregnant with my first child, when I learned that my maternal grandmother, a sweet 80-year-old lady, had died of breast cancer. My journey has evolved from concern for loved ones, to learning to be a patient patient, to celebrating every success along the way. Cancer has led me to an appreciation of life that could not have existed without it.

Theoretically my mother's side of my childhood family is not afflicted with genetically-linked cancer. However, this genetic "fact" has been challenged in real life repeatedly. My mother was diagnosed with breast cancer in the 1990s, soon after her brother was diagnosed with prostate cancer. She was genuinely strong in every respect for as long as possible, but her cancer metastasized before long and she wasn't doing well. Even as I felt sad for Mom, I struggled with unresolved family issues. As her health deteriorated further I wished for reconciliation, and began my informal study of *Forgiveness*. And in my heart I forgave all of my childhood family as well as myself. In 1996, my three daughters and I, then ages 15, 13 and 10, started to participate in the Susan G. Komen Race for the Cure in my mother's honor. At the annual race, we saw friends who, like us, had a personal interest in racing for a cure for breast cancer.

In 2001, I went for my much dreaded mammogram. And that

year, unlike previous years, it was not "fine." This time I needed a biopsy which led to a diagnosis of Ductal Carcinoma In Situ. DCIS is the presence of abnormal cells inside a milk duct in the breast. I opted to have a bilateral mastectomy and reconstructive surgery. I was fortunate that all went well and no further breast cancer was discovered.

Three months later I was ready to pursue the dream that I had been contemplating for several years before my diagnosis. I had started to moonlight as a private tutor, and beating DCIS gave me the inspiration to quit my "day job" (academically oriented, but not teaching) and step into entrepreneurship. My business was going well, when approximately three years later I was "visited" again by cancer. This time it was a brain tumor that was confined to an area near the top of my head. Again, I was blessed it was removable, and despite some bad headaches, I again recovered completely and quickly.

More than ten years went by with many changes in my life. In 2011 I married the great guy I had met three years earlier, and within six months became the grandmother of two girls. My business, *Suzanne the Tutor*, continued to thrive, and I took piano lessons.

Then I was backing out of my driveway, on the way to tutor in the fall of 2017, and I collapsed behind the wheel. Although I regained consciousness almost immediately, I was taken to the closest hospital emergency room. In the ER, two of my medical tests revealed concerning spots on my lungs. Then surgery to remove the malignant tumors revealed cancerous lymph nodes. I was

facing Stage 3 non-small cell lung cancer! I was given a 30% chance of survival!

I had my first chemotherapy treatment on Thursday, September 6, 2018, and by that weekend I felt increasingly fatigued, depressed, and sicker than I'd ever been in my life. I saw my oncologist who let me know that I was fine; I was experiencing no unusual effects of the Cisplatin Chemotherapy. As I left his office I knew I could cope with my chemo; I knew I could survive lung cancer! After completing chemotherapy, while anticipating radiation treatment, I received the news that my daughter had been diagnosed with breast cancer.

After radiation went well, my doctor recommended that I consider a year of monthly durvalumab, a type of immunotherapy typically used for patients with inoperable lung cancer; I would be receiving this therapy outside of protocol. I jumped at the chance!

Throughout 2019, I received my monthly infusion of immunotherapy, and felt well, even normal most of the time, and spent as much time as I possibly could traveling to and from Rockville, Maryland to help my daughter. She is the mother of two small children and also endured surgery, chemotherapy, and radiation. We are both now in remission; we are both moving forward in our lives.

On March 1, 2020, on the eve of the Coronavirus pandemic, I had a party to celebrate; the banner hanging on the entry room wall of my house read, "I used to have cancer." I had used that phrase at Dunkin' Donuts after I was officially deemed "in remission," and the clerk had given my husband and me free muffins.

Head and 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>.

*Please check availability of these meetings during the ongoing Covid-19 pandemic.



Jonas T. Johnson, MD

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Dr. Johnson learned that patient care was inadequate, and a more comprehensive standard of care was needed with long-term follow-up care.

In the years since the Clinic has grown, it now includes surveillance (checking people for recurrence), prevention, assessment, and help in navigating the health system.

"The first thing I've done is try to help people understand what was missed and how there's this huge opportunity to do better in the future," says Dr. Johnson.

Dr. Johnson is also passionate about health literacy or helping patients understand what is happening. He is also concerned about the burden of the caregiver and financial toxicity. With three million data points, Dr. Johnson has the perfect ammunition to educate other doctors, who, he says, love data.

And now, after participating in several chairman searches in other departments, Dr. Johnson is helping with his own.

"It is my enduring belief that the key aspect of outstanding organizations is successful succession," Dr. Johnson says. "I believe that my successor will be better than me, and I fully want that to happen. They'll have all these new things to work on that will make the future brighter than the past."

A dietitian's role in head and neck cancer

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using a feeding tube to meet nutrition needs. Feeding tubes can be placed in the nose or in the stomach and provide liquid nutrition through the tube to meet their needs. Dietitians work with physicians to help make sure that patients who are receiving this method of nutrition meet their calorie and protein needs in addition to hydration.

UPMC has a variety of dietitians available to meet the needs of patients. We are located in many of the cancer centers, the Head & Neck Cancer Survivorship Clinic, and associated in an outpatient setting with many of the individual hospitals. If you are interested in meeting with a dietitian to help with your individual nutrition needs, ask your medical oncologist, ENT surgeon, or the Head & Neck Cancer Survivorship Clinic to send a referral for medical nutrition therapy or nutrition consultation.

Contact information

American Cancer Society.....	1-800-227-2345
Assistance with Coping.....	412-623-5888
Cancer Bridges.....	412-338-1919
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
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
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.
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412-647-2811

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