# 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 steps down as chairman

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



Dr. Jonas Johnson, chairman of the Otolaryngology department at the University of Pittsburgh School of Medicine, is stepping down (or should it be aside?). Dr. Johnson 's plans call for continued leadership and work in providing coordinated care through the Survivorship Clinic at Eye and Ear Institute. The clinic was established by Dr. Johnson and Dr. Marci Nilson in 2016. It provides a unique collaborative multidisciplinary evaluation with coordination of care for survivors diagnosed and treated for cancer of the throat. To date, over 3,500 visits have been accomplished. The survivor clinic seeks to better understand

how treatment alters people's lives. Each visit begins with a survey on a tablet. Patient responses help the treatment team know how the visit might be structured and where there may be opportunity to help the participant. Professional evaluation by the physician and nurse are supplemented through the services of an audiologist (hearing testing), a speech language pathologist (swallowing expert), a physical therapist, a dietitian, and a dentist. Referral to other specialists such as behavioral health and sleep specialists are routinely arranged.

Dr. Johnson grew up in Jamestown, New York in Chautauqua County. After completion of his training in Otolaryngology, he served in the United States Air Force in San Antonio, Texas. In 1979. Dr. Johnson, his wife and three small sons moved to Pittsburgh, and he began working at UPMC.

For 40 years, Dr. Johnson's main efforts have been the surgical care of patients with head and neck cancer. Dr. Johnson has always been surrounded by medical students, residents, and Head and Neck Surgical Fellows. These young specialists currently are leading otolaryngologists in large cities and towns around the country (and the world). Many serve as faculty in the leading academic medical centers in the United States. The care of patients has always included use of a tumor registry to allow the study of the outcomes of treatment. The information derived from these studies has resulted in the publication of medical books, book chapters, and hundreds of manuscripts in the medical literature.

Dr. Johnson was appointed chairman of the Otolaryngology Department in 2005. During his term of leadership, the department grew to over 50 faculty and established clinical sites at St. Margaret's Hospital and Mercy Hospital, in addition to sites at Shadyside Hospital, Children's Hospital, and Eye and Ear building in Oakland. In 2016, Dr. Johnson stepped away from surgery to devote his efforts to the establishment of the Survivorship Clinic at Eye and Ear Institute. The clinic is the first of its kind with the principle of treating a head and neck cancer survivor in one location at a one-time fee.

### **Believe**

By Kelly Wickersty Cancer survivor and Mrs. Claus Club of North Hills recipient



Throughout my journey I have met so many survivors, thrivers, and previvors who have blessed me with wisdom, strength and inspiration.

Cancer is a very individual experience. Each and every person, whether a survivor or someone who loves someone with cancer, has a unique journey.

I have pulled moments of great strength as well as joy and laughter from a note, a card, a prayer, a friend sitting with me, and listening to and experiencing the knowledge of those who have gone before me. I in turn endeavor to leave behind whatever I can that will benefit those who will walk the path after me.

Believe...one simple word has so many profound lessons. Through my journey, believing in prayer, believing in others, and believing in myself has allowed me to be here today.

### Believe in prayer

I stand confident in the overwhelming, never-ending love of God. Prayer is the anchor of the Mrs. Claus Club ministry, as well as the anchor of my journey. My heart is joyful today because cancer took nothing from me, but gave me the relationship with God to speak to him about what was truly important in my time here on Earth. I have gratitude that my beliefs have unlocked the truths of my life. It turns my challenges into gifts, my failures into successes, the unexpected into perfect timing, and my mistakes into important events.

After college, my mother was diagnosed with breast cancer. I prayed for her to find strength in her journey, and she is here with me today as my mother, my friend, and a survivor 15 years cancer-free.

At age 31, my fiancée was diagnosed with stage 3 gastroesophageal cancer. His diagnosis included a 15% chance of 5-year survival. I prayed through his treatments and surgery that we would have the opportunity for the life that we dreamed of together.

We were married on November 19, 2011 and last November we celebrated ten years of marriage – in good times and bad, and in sickness and in health. After our wedding, when we hoped to start our family, my doctors found over a dozen sites to breast biopsy. I prayed that God's timing in my life left a window through which I would be able to have children and be a mother. My prayers were again answered and we were blessed with our son, and a year later, our daughter.

When our children were toddlers, I had my first breast cancer diagnosis. I prayed that I could have a few more years, to get through the pick-them-up-every-second phase of parenting; the high chair, car seat, bath tub, and crib phases of childhood, before needing a major surgery.

Last summer, by the grace of God, we caught another breast cancer diagnosis, and again my prayers were answered; God's timing allowed my children to be school-aged, and old enough to understand I would need to have surgery in my search to stay healthy. I was stubborn in my determination not to have a double mastectomy. I looked for not only a second opinion, but really anyone in the Pittsburgh area that would agree with me. I couldn't find anyone, and finally I realized it was time. My prayers were answered again, and our amazing, kind, and beautiful 7-year-old daughter, Alessandra Grace, and our determined and strong 8-year-old son, Dominick Joseph IV, were the true little heroes of my summer. My belief and my relationship with God made sense of my past, brings peace for today, and creates the vison for my tomorrows.

#### Believe in others

It is amazing how far you are willing to go when someone believes in you, when they look in your eyes to your soul, and know you are strong enough to battle that phone call about a loved one or about yourself. Sometimes someone appears in your world unexpectedly, like a gift from the Universe. You didn't know you needed them, or that you had called out silently to them through your prayers. They come into your life when you need them most, to pray with you, sit with you, lift you, educate you, wake you up, or remind you of your strength. These humans awaken the truth that was

always in you, and patiently sit and watch your strength grow. For me, believing in the good in others was easy. It was believing in myself that was the real challenge.

### Believe in myself

I am proud to have had the journey I had with cancer. I believe there is a reason and a purpose that I am a survivor. Survivorship means you are alive to advocate for research, to help those who need help, and to gain a better perspective on what life is really about – loving others, giving and sharing.

Strength does not come from just beating cancer or getting through treatments. Every day your strengths are developed through your struggles, your treatments, researching options, and advocating for the ones you love and defining their end-of-life care. When you go through a cancer diagnosis, and accept the treatments and hardships, and decide not to surrender to negativity but to keep your head up and walk by faith – that is strength.

Mrs. Claus Club is an amazing organization that sees through tragedy and focuses beyond the cancer, to find purpose, to let people know they are loved and that they are not alone. This very perspective changes everything. It changes people and their journey and allows them to focus on believing.

Thank you for letting me share my story, and for being part of my journey.

### No April Fools Joke

By Deborah Cooke Cancer survivor and Mrs. Claus Club of North Hills recipient



Deborah Cooke and her husband George

No April's fools, 2019. I received the anticipated phone call, and it was no April fools joke. The biopsy revealed ductal carcinoma in situ... I had breast cancer.

Earlier in the year, I underwent a lumbar/ laminectomy with a short recovery needed. Then in October, I was hospitalized for pulmonary vein isolation ablation. Piece of cake. To start off 2020 I had outpatient surgery for squamous cell carcinoma under one eye which was unpleasant. April 1st, 2019, was the start of my breast cancer treatment journey. In March my gynecologist noticed a bruise above my right breast. I knew the cause, but he wanted me to have a mammogram anyway. A small mass was detected in my other breast! Only through God's grace was it found so early. A biopsy was scheduled. Later pathology showed it to be a very aggressive type. I don't want to imagine the diagnosis months later through a yearly mammogram.

I telephoned my older daughter, and we set a time for us to sit down with my teen grandsons to tell them of this diagnosis. She started researching breast cancer. I telephoned my other daughter who is a vice president at Geisinger Health System, and she was searching the internet while we were still on the phone! She spoke with several colleagues, sending lots of information for me to digest. She was also questioning me throughout, making sure I was traveling the best path on my treatment journey.

From the beginning, my doctors and their staff carried me tenderly through by setting appointments, etc. A partial mastectomy was performed with radiation to follow. I have to mention that, because of a stroke a few years prior that resulted in my having less than half of my eyesight, I am legally blind and unable to drive; therefore, my husband has to drive me to all my appointments. Thankfully, I am able to function navigating through stores and airports.

During this time, I received a surprise package from Mrs. Claus Club of North Hills containing a variety of gifts that I might need, including practical items along with personal things. It really was like Christmas! That very day I received a loving phone call from a Mrs. Claus Club volunteer. She asked me how I was doing, any needs, and, most importantly, she asked if I wanted her to pray with me. What a blessing. She checked in with me through the weeks. A true blessing. My dear friends had submitted my name to receive this wonderful gift. No cost involved. Since then I have submitted names of friends to be blessed and

prayed for. I have also donated in various ways to this volunteer organization so that it may continue to thrive and be of help to people who find themselves having to travel this unplanned cancer journey. I used to have cancer!

### **Choose to Live**

By Cara Caitlin Cancer survivor and Mrs. Claus Club of North Hills recipient



Nothing about a cancer diagnosis is enviable.

It is terrible to find out that something is in your body trying to kill you. It is frightening to find out what it takes to kill it! When cancer declares war on you, it is a fight to the death. Choose to live. Kill the cancer.

As a personal trainer and yoga instructor, the only thing I knew about cancer was what to eat to best avoid it and the benefits of staying active. I have never smoked, I don't stay in the sun too long, I have been careful about the products I digest, use on my skin, and use in my home. The cancer I was diagnosed with did not care about any of that!

As a military spouse, I started 2020 moving to a new house on the opposite side of the country, where I was greeted by the pandemic shutdown for a year. When I emerged after receiving my first vaccination, I was hired at a new job location and had started to fill my schedule with vacation plans. Before starting that, I went to the hospital to have a lump I discovered in my left breast checked out.

When my appointment began, nurses praised me for my "excellent health." When my appointment ended, my doctor told me that I had cancer. I was alone and was absolutely stunned to hear that I had to begin a 2+ year treatment immediately.

Every plan in my book was erased. At that time, everything in my life changed. First, I cursed, then I cried, and then I decided the fight was on!

As I signed the consent forms that listed the possible side effects I could experience (even warning of the future cancers the treatments could cause), I chose to stay focused on what I was choosing and why. I was choosing every step of the uncomfortable treatment to stay alive! I never felt like a victim to the cancer or the medication and therapy. I knew I would survive this battle.

With a fight song on my lips, and pep-talks in the mirror, I joyfully received my 20 weeks of chemotherapy. I came to love the infusion room. Truly, I was giddy when I got there, not for the pain and discomfort of the infusion, but because I was passionate to my core about getting that cancer out of me.

Honestly, the biggest fears I experienced came from things my doctors and other people would say to me. I learned to not look up the details others shared online - when all they were doing was complaining about going through the very thing I was going through. My doctors were warning me every week that the next week is when it would all change and I'd have to give up my active lifestyle, and I needed to be preparing myself for that. I shocked my oncologists when I started sharing my weekly workout videos with them. There was so much disbelief, that one doctor checked with the pharmacy to confirm that I was indeed receiving all the proper chemotherapy. I was.

Were there times that I was tired? Yes. Were there side effects I was feeling? Yes, more than I can list. Was there pain I experienced? Yes, yes, yes. Did any of it stop me from living my life fully through treatments? No!

I practiced yoga nearly every day and I weight trained and danced at the gym six nights a week. After an infusion, I flew alone to Miami to meet my husband for vacation. In between two treatments, I even rode the front seat of every roller coaster at Cedar Point! I traveled to California before my surgeries and stayed active through eight weeks of daily radiation.

The key for me was mindset, and never losing sight of the life I was fighting for. Other people said I needed to be scared through treatment, I needed to be afraid

of future cancers, and that I should live in fear of this for the rest of my life. Those were their fears! I did not let them become my own. I did not let the worry of "what ifs" dictate my life. I acknowledged that the difficult moments were temporary. I listened to my body and gave it what it needed when it needed it. I did not compare myself to anyone else. I did not accept pity from others. I never felt self-pity – it would have used up the energy that I needed to battle against the thing that wanted me dead.

I accepted love when it was offered. I appreciated support. I was beyond thankful that I had access to care and treatment to assist my fight and help me win. I often acknowledged those who came before me (from donors, to scientists, to doctors, to patients) who provided the many years of information needed to make my diagnosis one that was curable.

As I write this in May of 2022, I am tumor free and about to begin the next year of oral chemotherapy and hormone therapy. I will invite the medication to do its work and I will continue to be thankful and celebrate the help it gives me.

Even in the darkest times, and scariest moments, we have choice. When unwanted situations burst into our life, we don't have to let them define us. If you are faced with a fight against cancer, make that fight your number one priority, choose to kill it, and be the one that lives!

I would like to add a special Thank You for the incredible support offered from the Mrs. Claus Club of North Hills. I can personally speak to the help their baskets offer to cancer patients, like me.

To hear more about her journey, you can find Cara Caitlin on Facebook or Instagram @QuestsWithCara.

### Mrs. Claus Club providing comfort baskets to men and women battling cancer

By Jeana Watenpool Founder and President, Mrs. Claus Club of North Hills



The Pittsburgh North Chapter of the Mrs. Claus Club is a non-profit organization founded in 2009. We are a group of Godly women dedicated to helping others during this battle for life. Each member of our board has seen someone close to them struggle with cancer.

#### Our Mission...

We provide comfort baskets to men and women who are undergoing cancer treatments, bringing hope, encouragement and the opportunity to pray for each recipient. By networking with local cancer treatment centers like Women for a Healthy Environment, Cancer Bridges, and Creative Hair Solutions, we are able to provide the best comfort items in our Believe Comfort Baskets. Our comfort basket includes a

cookbook, mouthwash, ginger candies, journal, tea, gum, lip balm, hand sanitizer, note cards, gift card, devotion, prayer shawl, pillow case, port pillow, & many more items.

One truly special and unique item in each comfort basket is a prayer shawl, which is knitted by women who donate their talents and time to this worthy cause. As the shawls are knitted, prayers are said over each stitch for the future recipient who will be blessed with the shawl. The same holds true to our sewers of pillow cases and port pillows.

When battling cancer, even on "good days" the mirror will give someone a painful reminder of their struggle. Our basic goal is to make sure they realize they are not alone and to provide some sense of normalcy during this difficult time, even if only cosmetic, and the opportunity to pray for the recipient.

The comfort basket gets us in the door, but we love being able to spend time with the recipient, and give them hope and encouragement for their cancer journey, and BELIEVING for a miracle healing.

# Prayer is the anchor of our organization

Our organization doesn't simply drop off the basket and move on to the next recipient. Forever friendships and connections often develop from these visits. When a basket is delivered, we visit with the patient, explaining the items in the basket and the purpose of the club. Often when we walk into a home or cancer center, the recipient looks defeated. After receiving the basket, visiting together and having the opportunity to pray, a change has taken place. The recipient's hope has been restored.

For more information, or to knit/crochet a prayer shawl, send an email to MrsClausClubNorth@gmail.com, call 412-992-7339, or visit MrsClausClub.org.

When you have a friend, family member or co-worker diagnosed with cancer, this is one way you can rally around them, by providing hope for their journey by requesting a comfort basket.

Together, we can make a difference.

### **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.

### Enhanced Recovery after Surgery (ERAS) in head and neck surgical oncology

By Mark Kubik, MD Assistant Professor, Department of Otolaryngology – Head and Neck Surgery; Department of Plastic and Reconstructive Surgery



Patients with head and neck tumors often require major oncologic and reconstructive surgery for management of their disease. These surgeries are laborious,

extended procedures requiring multiple surgical disciplines to address a complex surgical problem. Very often, surgery is recommended in patients with complicated medical histories and prior non-surgical cancer treatment (e.g., chemotherapy or radiation), which further elevates the risk.

Enhanced recovery after surgery (ERAS) refers to research-based, patient-centric perioperative care protocols designed to optimize the patient experience and reduce the risk of complications before, during, and after surgery. These protocols were first developed in the setting of major colorectal surgery and have since been applied to several surgical disciplines.

At the University of Pittsburgh, we care for a high volume of patients undergoing major head and neck surgery. Our multidisciplinary reconstructive team, composed of microsurgical experts in otolaryngology and plastic surgery, plays a major role in the care of these patients. The ability to perform "free tissue transfer" to reconstruct defects after cancer surgery has several benefits, including a reduction in head and neck wound complications, improved function, and improved tumor margin clearance during surgery. Our team currently provides complex reconstructive care to several hundred patients on an annual basis. Given the volume, it has been a major emphasis of our team to

develop an ERAS pathway for our patients. This has been developed in collaboration with the Center

for Perioperative Care (CPC), UPMC's surgical prehabilitation clinic.

The goals of the new care pathway are numerous. They set forth recommendations for anesthesia care, optimizing patient nutrition, postoperative nursing care, and standardizing pain management.

It is no secret that the United States is very much in the midst of an ongoing opiod misuse epidemic. The ramifications of the current problem are massive, and unfortunately, narcotic dependence in head and neck patients often begins after major surgery. A major focus of ERAS, therefore, is pain management and the judicious use of narcotic medications.

Our ERAS protocol here at the University of Pittsburgh takes a proactive approach to pain management, as opposed to a reactive one. Key principles include the treatment of pain prior to onset, multimodal therapy (treatment with multiple non-narcotic drug classes), and use of nerve blocks during and after surgery.

With the implementation of our new care pathway, we hope to see improved pain management, reduced reliance on narcotics, shorter hospital stays, and expedited recovery. Efficient recovery after surgery is critical not only for patients' general health, but also for their cancer prognosis. There is ample evidence that shortening the time between surgery and subsequent cancer treatments improves cure rates in several malignancies.

The standardized use of the Center for Perioperative Care (CPC) is inherent to these efforts. The CPC is a relatively new clinical endeavor at UPMC that focuses on assessing the risk of surgery, providing risk reduction strategies, and fostering improved patient understanding of their disease and prognosis. The CPC is a clinic run by the Department of Anesthesia at Montefiore Hospital. Recent data has shown that a standardized system of



preoperative patient evaluation in the CPC reduces surgical complications, readmissions, and improves several other outcome metrics.

In summary, ERAS protocols at the University of Pittsburgh represent an exciting advance towards standardized, high quality, and innovative surgical care for patients with tumors of the head and neck undergoing major surgery.

# Sleep problems in the context of cancer

By Jennifer Steel, PhD Director, Center for Excellence in Behavioral Medicine; Director, Quality of Life program for UPMC's Liver Cancer Center; Professor of Surgery, Psychiatry, and Psychology, University of Pittsburgh School of Medicine



The Center for Disease Control estimates that over 70 million people suffer from chronic sleep problems. Sleep problems are prevalent in cancer patients, with 45-80%

reporting poor sleep quality compared to 29–32% in the general population. On average, cancer patients report sleep duration of 4.8–7 hours per night while sleep duration in the general population is between 6.5 and 7.5 hours per night.

Research has shown that approximately 80% of cancer patients believe that their sleep problems are caused by the treatments associated with cancer, and 60% believe their symptoms are temporary, However, sleep problems have been reported to persist long after cessation of treatment for cancer.

Sleep is critical for mental and physical health and overall quality of life. Sleep problems increase the risk for depression and anxiety and can exacerbate fatigue and decrease one's ability to concentrate. Chronic short (less than 6 hours) and long sleep duration (greater than 10 hours) has been linked to increased risk of mortality in the general population and in those diagnosed with cancer.

Approximately 60% of people sleep with a partner, so if one person is having sleep problems it increases the likelihood that their partner has disturbed sleep. For these *Continued on page 6* 

### Sleep problems in the context of cancer continued from page 5

reasons, it is important to appropriately diagnose and treat sleep problems to improve quality of life and decrease morbidity and mortality associated with sleep problems.

The most common sleep problems are sleep apnea followed by insomnia and restless legs syndrome. While other sleep disorders are rare (e.g., narcolepsy, idiopathic hypersomnia, night terrors, REM sleep behavior disorder) it is important that these disorders are diagnosed and appropriately treated.

Sleep apnea, the most common sleep problem, once diagnosed, can be treated with assisted breathing devices (e.g., continuous positive airway pressure ventilation) or dental devices. Insomnia, the second most common sleep problem, can be treated with medication, but it is often not recommended for long-term use due to interactions with other medications, risk of falling, and risk of physical and/or psychological dependence.

The gold standard for treating insomnia is cognitive-behavioral therapy. A psychologist or sleep expert (e.g., physician, nurse) can diagnose and provide treatment for insomnia. Cognitive-behavioral therapy for insomnia (CBTi) includes improving sleep hygiene, stimulus control strategies, and identifying and changing thoughts that may contribute to sleep problems. The behavioral aspects of CBTi include changing behaviors that may contribute to poor sleep including using coffee, tobacco, or alcohol before bedtime; eating a big meal within three hours of going to bed; using electronics in bed; and/or not having a ritual associated with sleeping.

Stimulus control techniques to improve sleep include using your bedroom only for sleep (and sex); making the environment conducive to sleep (e.g., dark, quiet); getting out of bed after 20 minutes if you cannot sleep and doing a boring activity before going back to bed; going to bed and waking up at the same time every day; and/or not napping during the day. With advancements in technology, there are mobile apps and internet-based programs available to treat insomnia (e.g., SHUTi).

The third most common sleep problem is restless legs. Restless legs is often treated with medication including iron supplements, antidepressants, and/or calcium channel regulators. Diet (e.g.. iron rich foods) and exercise are also important to reduce the symptoms of restless legs.

While sleep problems are prevalent in those diagnosed with cancer and their intimate partners, there are experts to diagnose and treatment of sleep problems at the University of Pittsburgh Medical Center. Treatment of sleep problems is critical to improve quality of life and reduce the risk of morbidity and mortality associated with sleep problems.

### **Contact information**

### 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.

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