

HEADWAY

SINCE 2007

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

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Ototoxic effects of platinum-based chemotherapy and radiation

By Catherine Dymowski, BA Communications Sciences and Disorders,
University of Pittsburgh

Communication Facilitator, UPMC Department of Audiology



Hearing loss and tinnitus are common side effects among survivors of head and neck cancer. This can be attributed to a combination of platinum-based chemotherapy agents and radiation treatment focused on the head and neck area. Platinum-based chemotherapy drugs are widely used due to their effectiveness in cancer treatment. When a certain drug is considered ototoxic, it means that the effects of that drug can cause hearing loss, tinnitus, and problems with balance. Due to the proximity of the radiation to the cochlea and the ototoxic effects of platinum-based chemotherapy treatments, there is a heightened risk for hearing loss and auditory-related issues in

survivors of head and neck cancer. Platinum-based chemotherapy drugs have been shown to damage cochlear hair cells, neurons, supporting cells, and other areas in the hearing system responsible for blood flow. These damaging effects can lead to hearing loss that is typically bilateral (i.e., occurring in both ears) and irreversible. Cisplatin (considered the most ototoxic), oxaliplatin, and carboplatin are commonly used chemotherapy drugs that fall into this category.

The American Speech-Language-Hearing Association (ASHA) and the American Academy of Audiology (AAA) have both stressed the importance of monitoring ototoxic drug effects in survivors of head and neck cancer. It is recommended that all patients undergoing radiation and cisplatin chemotherapy have a pre-treatment baseline test, as well as a post-treatment hearing test every six months for up to two years following the completion of treatment. Recent studies found patients rarely follow up for post-treatment hearing tests, which may indicate people are not accessing hearing care that might improve their communication in work, social, health care, and family situations.

Dr. Jonas Johnson and Dr. Marci Nilsen created the UPMC Head and Neck Cancer Survivorship Clinic to help cancer survivors improve their quality of life and manage late and long-term post-treatment cancer symptoms. In 2016, Dr. Catherine Palmer, Director of UPMC Audiology, worked with Dr. Johnson to integrate audiology services into the clinic to aid in hearing loss detection and management among cancer survivors. The goals of providing these services are twofold: the first goal is to identify hearing loss that may interfere with the patient's communication during their medical appointments and intervene to facilitate optimal communication. This typically happens with the use of a

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Cancer: A 25-year journey

By John S. Nicotra
25 Year Head and Neck Cancer Survivor

Friday, October 2nd, 1998, during a routine teeth cleaning, the hygienist noticed an abrasion on the inside of my right cheek. She had the dentist look at it. He suggested I have an Oral Surgeon check for cancer. A biopsy verified it was cancerous. Within weeks, the cancerous tumor was surgically removed. The margins were clear. No need for further treatment. Nine months later, a second tumor developed under my chin - again cancerous. Radiation and chemo shrunk and destroyed the tumor.

Over the span of 17 years, on 13 different occasions, suspicious growths inside my mouth were found to be cancerous, resulting in 12 surgeries, two flaps - one on each cheek were required to replace my cancerous cheeks.

Early on, my wife and I agreed that we would share with our five children any of our serious health issues. Once our doctors verified the potential serious decisions and consequences of our health issues, our children were informed.

There are three factors that have been critical in my battle with cancer - **Faith, Family and Attitude.**

Faith in Jesus Christ. I trust Him with my life. I know He's capable of performing miracles - even now. I believe I'm one of those miracles. My wife and I also had faith in the doctors and the other medical professionals who were involved in my treatment. We discovered trusting the medical professionals helped soften the doubts and concerns we had.

Family. Our family and close friends supported my wife and me through all of the treatments and recoveries. Without their love and support, our struggles would have been much more difficult. I feel sorry for those who don't have strong family support. Knowing you are loved by many and they'll be with you through the dark days as well as the good days is very comforting.

Attitude. On Word FM 101.5, I've listened to Chuck Swindoll for many years. He has a saying, "Life is 10% what happens

to us and 90% how we handle it." A positive attitude has been critical in the success in overcoming the difficult times I've encountered.

Besides cancer, three other difficult challenges we've had to endure in the last 11 years include the sudden death of our grandson J. R. (25 yrs. old) who drowned in a boating accident. Another grandson, Matthew, died suddenly on May 13th, 2017 (35 yrs. old) due to a serious infection. I thank God my wife and I were able to be there to comfort and support our son Jay, and our daughter Valerie in the loss of their children. In mid-June of 2017, my family and I confronted the third difficult challenge. My wife, Mary Ann, was diagnosed with liver cancer. She was taken home to be with our Lord on January 13th, 2018. I also believe that another reason God kept me alive was to give me the opportunity to care for my wife, my soul mate, through her illnesses. In that same 11 year timespan, I was hospitalized five different times for cancer surgery.

We all choose to handle difficulties in different ways. We decide what's best for us, for our spouse, our children, our friends. How we handle our diversity can positively and/or negatively affect those most dear to us. It's your choice. As Don Porter wrote: "Don't waste your cancer!"

Through the experiences with cancer, and the other life altering lessons I've lived through, I've learned I am much stronger than I ever imagined. I've learned I am loved by many more people than I ever dreamed. Most importantly, I've learned I am not alone in life's journey because God holds my hand every step of the way. God Bless.

But I still have days

By Jim Lamagna
Cancer Survivor

In November of 2021, I began having pain in my back. After a couple of days, the pain got stronger. I told my wife of the pain and said I think it was caused by kidney stones. Not being fond of visiting doctors, I decided to drink gallons of water, to pass the stones. After several days, no stones passed. My wife convinced me to visit a doctor for a diagnosis. He suggested a CT scan. Due to COVID, the earliest it could be performed was the end of January.

Walking was very difficult - controlling my legs was a major challenge. My wife suggested we go to the ER on January 1st. Both a CT scan and MRI were performed. Findings showed tumors were pressing on my spinal cord, and broken vertebrae at T-10 and T-11. Cancer cells had weakened my bones, resulting in breaking my back.

The moment the "C word" came out of the doctor's mouth, I went numb - not hearing anything else. Being told I had cancer turned my world upside down. Due to the COVID surge, only my wife could visit me in the hospital. Not being able to have our four daughters and two grandchildren visit me was hard on all of us. I was overcome with guilt. I felt I had let my wife and children down. My mind led me to believe the cause of the cancer was due to my smoking and poor eating habits.

The hospital staff and doctors were so wonderful to me. Two of them especially



John Nicotra (center front) at the wedding of his grandson T. J. Nicotra and his new wife, Maddie



Jim Lamagna (center) with his wife, children and grandchildren

kept telling me the cancer wasn't from smoking or improper diet. After a few days, surgery on my back to repair the broken bones along with spinal cord separation surgery was performed. Biopsies were performed on tumors on my legs, hips, and prostate. The diagnosis was Stage 4 prostate cancer that spread throughout my body and bones. After two weeks, I was discharged from the hospital.

For a couple of weeks, I was bed-ridden. Once I regained feeling and strength in my legs, I was able to walk with the aid of a cane. Treatments began with precise radiation on my back, then radiation on my prostate, hips and legs were performed over two months. The radiation treatment was very difficult. It seemed rather than making me feel better, I would get sicker. The last week of radiation treatment was by far the worst.

Daily hormone therapy drugs to help reduce the tumors' growth are part of my treatment. I receive a shot quarterly of Angrogen Suppression Hormones to slow the growth of the tumors. Currently I am scheduled every three months for testing and scans to check on the progress of the drugs. My stamina is very poor and I lack strength, but I make the best of each day.

In August of 2022, I went back to work. My purpose was to be an inspiration, a beacon of hope to my fellow workers. I was doing way, way better than anyone thought I was going to do when I was first diagnosed.

On March 1, 2023, I decided to take a

leave of absence from my paid job. I decided my primary responsibility is to focus on healing instead of working! It takes a lot of mental and physical effort to heal. I am blessed to have my loving wife, beautiful daughters, and wonderful grandson and granddaughter who motivate me to fight every day.

I want to be proof that staying strong, believing in God, in prayer, and never giving up will help you through each day.

I have good days. I have bad days. But I still have days!

My current challenge ...cancer

By Robert Kirsopp
Cancer Survivor



Robert Kirsopp with his wife

Before he said a word, I could see it in Dr. Voth's eyes. But I was a million miles away when he told us. I just shook my head and agreed with him like I knew what he was talking about. Shock had set in, and it was spreading fast to my

beautiful wife. I could see the disease spreading like a plague. The look she gave the doctor of the unknown is when I knew I had to be strong for my family, and I was going to beat cancer.

In my head, I could hear my drill sergeant screaming at me, "Lead by example Private Kirsopp, lead by example Hooah!" And my father telling me to do the job the right way the first time, but not quite using those same words.

My testimony in fighting cancer is I have always been into challenges. I'm sure it has to be my upbringing. I can't say it was the easiest of all childhoods, growing up on a horse farm in Eighty-Four, Pa. and helping my dad with his roofing side business. But it gave me a great perspective on life and work ethic.

When encountering a difficult challenge, I say to myself, someone else has survived going through the same struggle, and someone has it worse than me.

After graduating high school, I entered the US Army and was placed in some wonderful places and some not-so-great places. Being away from family and friends was stressful, but we survived.

It was in one of those not-so-great places I started to have conversations with God. I wasn't raised in a very religious household, but when there are people actively looking to kill you, it might be a good time to start having those types of conversations. My takeaway from these conversations is that God has a plan for me. If He chose for me to come home to Him, then it was just my time. But if He gave me more time on Earth, then I have a purpose here, and I should lead by example and always do my best.

I believe God throws challenges at us to see how we deal with them. I'm not saying I'm the best at handling them, but I'm pretty good at accepting them.

Getting through school, the military, the police academy, getting hired, finding a great wife, starting a family, and raising great kids are all some of the challenges I've had in my life. Oh there have been others, but let's focus on the positive.

My cancer challenge came In April 2019. It went from finding just a little blood, to visiting my doctor, getting that colonoscopy and then learning that I had Stage 4 rectal cancer that had spread to my

Dr. Marci Nilsen receives prestigious fellowship



It was recently announced that Dr. Marci Nilsen, RN, PhD, who, along with Dr. Jonas Johnson are co-founders and co-directors of the UPMC Head and Neck Cancer Survivorship Clinic, is one of 16 members admitted to the 2023 Betty Irene Moore Fellowship for Nurse Leaders and Innovators. This program recognizes early- to mid-career nursing scholars and innovators and requires they take part in an innovative research project or study. Each fellow receives \$450,000 over three years to develop their leadership, innovation and networking skills while completing an innovative project. Funding includes an additional \$50,000 to the fellow's home institution to support the fellow's 30% time commitment. Fellows complete a dynamic leadership and innovation development program hosted by the Betty Irene Moore School of Nursing at UC Davis in collaboration with the UC Davis Graduate School of Management

Dr. Nilsen's fellowship project will focus on improving symptom management during cancer treatment in under-resourced diverse settings. Dr. Nilsen plans to utilize the skills and knowledge derived from serving over 4,000 patient visits since the inauguration of the Survivorship Clinic in 2016

Her aspiration is to provide coordinated survivorship care to patients with head and neck cancer who cannot, for logistical reasons, avail themselves of these services. During the fellowship Dr. Nilsen will continue to co-direct the UPMC Survivorship Clinic

Dr. Nilsen's mentor in this fellowship is Margaret Rosenzweig, PhD, FNP-BC, AOCNP, FAAN, Distinguished Service Professor, University of Pittsburgh School of Nursing, and Professor of Medicine, University of Pittsburgh.

liver and several other areas of my body.

I chose to beat cancer by leaving my care not just in God's hands, but by finding that warrior spirit. You can't beat me cancer, or maybe you can. But I'm going to fight like hell.

For four years now, with countless treatments and surgeries, you can't beat the support I've had. My family, friends, teammates, community, coworkers, and employer all have been great. There have been dark times, but it's this support that has pulled me back into the fight. I'm sorry, I know not everyone has this type of support. It's sad, but with organizations such as the Mrs. Claus Club, the support they give is powerful against this nasty disease. I learned of the Mrs. Claus Club late in my battle with cancer, but I've heard the testimonies of their value. THEY lead by example.

You never know who is watching as you work through life's challenges. In 2022, a close family friend and one of my son's best friends, who is only 16 years old, was diagnosed with cancer. I don't know if I set the example for him on winning his fight with cancer, but I know he showed me great will and fortitude as he just finished his chemotherapy.

Sun Tzu in *The Art of War* says "Victorious warriors win first and then go to war, while defeated warriors go to war first and then seek to win."

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Ototoxic effects *continued from page 1*

non-custom amplifier. Second, we aim to connect the patient to the audiology department to provide follow-up care. At the beginning of the visit, the audiology assistant will look in the patient's ears and screen their hearing with a series of tones. The hearing screening reveals a patient's responses at 1000 Hz, 2000 Hz, and 4000 Hz, which are frequencies commonly found in conversational speech. If the patient does not hear any of the tones, or is experiencing any difficulty with hearing during the visit, they are offered a non-custom amplifier throughout the visit to promote effective communication. It is important to screen hearing because over 70% of cancer survivors do not pass the hearing screening, and over half of those patients do not recognize that they have hearing loss. A screening is the most reliable way to identify an impactful hearing loss that can negatively impact healthcare outcomes. An audiologist is available to provide comprehensive hearing tests the same day for patients who do not pass the hearing screening, and otologists are also available to assist with wax removal services. Patients undergoing cisplatin and radiation treatment should have their hearing comprehensively tested either the day of their visit or at a UPMC Audiology clinic closer to their home, as well as follow the established guideline recommendations

for regular follow-up testing which includes testing every six months for two years after completion of treatment.

Ideally, all patients undergoing treatment would have their hearing tested. Working closely with an audiologist to identify hearing loss and create a rehabilitation plan can allow for more effective communication with loved ones and improve quality of life. For those undergoing treatment that is ototoxic, completing a hearing test every six months, or as often as you are able, allows for you and your audiologist to understand long-term ototoxic effects on your hearing and manage the effects accordingly. If you are a candidate for hearing aids and concerned about cost, please be aware there are programs available to assist financially with obtaining hearing aids. Please also be aware that tinnitus management services are available for those experiencing bothersome tinnitus. The UPMC Audiology Department is located on the 4th Floor of the UPMC Eye and Ear Institute. If you are planning to receive treatment for head and neck cancer, currently undergoing treatment, or have completed treatment, please contact the UPMC Audiology Department at 412-647-2030 to meet with an audiologist who can help you to address and manage your hearing and communication needs.

Cancer affects the entire family: a daughter's perspective

By Valerie Schmitt, RN-BC, CCM

When my father, John Nicotra, told me that he planned to write his story for *Headway* I was really surprised. He was asked many times over the years why he was always asking others to tell their story for his newsletter, yet he has never shared his own story. Then he reminded me that this is the 25th anniversary of first being diagnosed with squamous cell carcinoma of the cheek. My next thought was "Holy heck 25 years! He must be Doctor Johnson's oldest living patient!"



Valerie with her father John Nicotra and her mother Mary Ann at her nursing school graduation in 1997

I try to believe that everything happens for a reason. When I look back on my life, I know that God chose me as the eldest for a reason. He also gave me the incentive to go to school after my children were in elementary school. Since I am the only family member in the medical field, I became the "family nurse." My parents trusted what I told them because of this. Mom used to say that I could get away with saying things to dad that nobody else could. But he knew that I was only looking out for his own good.

My parents never kept things from us kids, so as soon as dad was initially diagnosed with cancer, my four siblings and I were told about it. We were all there for the surgery. According to the surgeon, they "got it all" and there was no need for any further treatment. We all felt a big sigh of relief and life went on – briefly. Unfortunately only nine months later dad's cancer returned. More surgery.

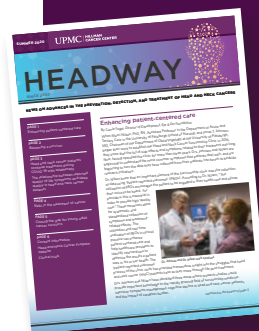
Chemo. Radiation. Mom was always at his side. At that time I was fortunate to work at Presbyterian Hospital, so I was able to meet

my parents at my dad's doctors appointments and ask questions that my parents wouldn't know to ask. Everyone needs an advocate and I was dad's advocate. As a nurse who arranged homecare for head and neck cancer patients, I was able to understand the procedures and what to anticipate. Dr. Johnson answered my emails promptly and honestly. He became a family member and even visited my mother when she was hospitalized. I shared this information and updates with my parents and siblings.

My dad was never able to get past the two year mark without recurrence of his cancer. Luckily it was always caught prior to metastasizing, but there were many surgeries, chemo, and radiation treatments to the point that chemo and radiation were no longer an option. Despite the recurrence of cancer every year or two, life continued. We went on our annual vacations to the Jersey shore – the whole tribe! The guys played pinochle and went on their golf outings, which was and is dad's therapy.

Because of all the radiation, dad developed osteoradionecrosis, or bone death. They had to remove his lower jaw. Dad also had an 18-hour surgery for a right cheek flap and a 13-hour surgery for the left cheek flap for recurrences. Mom and the rest of us waited, pulled together, and prayed. And God listened to our prayers.

I remember before my dad's first trach and flap. This was many years ago and it was early December. Dad just wanted to "get it done and over with." He had no idea what he was in for – and he planned to have the annual Christmas Eve party two weeks later with 50-60 people at my parents' home. I emailed Dr. Johnson about my concerns, as I knew this was a big surgery and was actually concerned that this could be my dad's last Christmas. Being an expert in the field, he was well aware that the recovery period for a surgery that involved could be lengthy. He also knew that my dad's days could be limited and that family meant the world to dad, so he suggested that dad delay the surgery until after the holidays and dad reluctantly agreed. That Christmas Eve was like all the other ones I can remember with the kids pumping the old player piano and singing carols, the annual grab bag exchange as well as



publications for archived issues of *Headway*.

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

the "surprise" appearance of Santa Claus. Mom spent days preparing enough delicious appetizers to feed an army and she always made sure we had a birthday cake for Jesus and the kids sang to Him. I just stood back and watched as my dad, the patriarch of the family, stood there taking everything in and smiling ear to ear. And I thanked God for convincing my dad to delay surgery until after the holidays.

The holidays were over and it was the big day. The surgery ended up lasting 18 hours. Mom and the rest of us sat quietly in the waiting room, taking up the entire room at times. We were all pretty quiet, not knowing when the doctor would come to see us or what he would tell us. When dad came out of the recovery room at 2:30 a.m. I didn't even recognize him, he was so swollen, but I anticipated he would look that bad initially. My mother and siblings were shocked. It took my dad close to a week in the hospital before he had the courage to look in the mirror. He cried. His life would never be the same. We all tried to support dad any way we could but, unless you've gone through it...

For the first month or two at home my dad sat on the couch all day long being depressed, with his Yankeur suction wand in his hand. After a while I started reminding my dad what I've always told my patients and I firmly believe which is that half the battle is your frame of mind. You can sit there and feel sorry for yourself or you can learn from your experience and move on. Finally dad gave up his security blanket, aka suction machine, and started getting off the couch, working on the computer. This was also when I noticed my dad's faith grow stronger and he prayed daily. As time went on, dad was back to himself and his scar became his "war wound." Dad

A daughter's perspective

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started up a cancer support group at his church. He passed out pillows to cancer centers that were made by a group of women. He started the publishing of *Headway*. He made lots of friends. Often my dad dragged my mom with him.

Life went on. After several more out-patient surgeries for recurrences, more family vacations, Easter egg hunts, golf outings, and enjoying life, my dad is 85 years old. Many people didn't think dad would see 85 years old. It did look grim for a while. Our family has lost a few close family members, some much younger than dad. Yet he is still here. And there is a reason. When my mother, the matriarch of the family, was diagnosed with liver cancer, Dad became mom's primary caregiver up until the end. I was glad that I was able to be there to support dad when he was forced to make some tough decisions. I updated my sister, who lives in Florida, and my brothers daily. Dad cooked for mom (for the first time) and mastered applesauce! He assisted mom in bathing, gave mom her meds, and between dad and the help of family, mom was able to enjoy her last Christmas at home (no big party) with her family. It was touching to see the love and concern that dad had for mom. It was also heartbreaking to see dad go through this. Dad always assumed he'd go first.

Evenings are lonely for dad after 60 years of marriage. He tries to stay as busy as he can during the day. Dad also lost his translator when mom passed, making communication difficult, especially on the phone. There are people who avoid contact with dad because they can not understand him, which is another barrier to socialization. He continues to be active, faithful, and involved with supporting and educating other cancer survivors. Dad's a fighter and his family still needs him, which is why he is still here.

My current challenge...cancer

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I can't say leading by example, accepting challenges, and having a warrior mindset are what you need to get through cancer but, so far, it's worked for me. While I have fought some large scale battles with cancer, I still have some smaller conflicts to win, but I intend on winning this war with cancer. Following the advice of Sun Tzu, I entered this war with cancer with the tools to win and the mindset not to lose. It's through life's challenges that we are able to develop these tools and tactics. My advice to you fighting this war with me is losing is not an option. We will stand and fight this together.

Contact information

American Cancer Society.....	1-800-227-2345 cancer.org
Breast Cancer Support Group - UPMC	412-647-2811
Cancer Bridges.....	412-338-1919 <i>Counseling, support groups, health and wellness, family programs</i> cancerbridges.org
Center for Counseling and Cancer Support - UPMC.....	412-623-5888
Division of Sleep Surgery - UPMC Mercy	412-232-3687 Monroeville..... 412-374-1260
Eye & Ear Foundation	412-864-1300 eyeandear.org
Face2Face Healing.....	724-935-3580 face2facehealing.org
Gumberg Family Library and Resource Center	412-396-6130
Hillman Cancer Center - UPMC.....	412-647-2811 <i>Research, clinical trials, referrals, patient resources, and support</i> hillman.upmc.com
Hopwood Library at UPMC Shadyside	412-623-2620
Hyperbaric Oxygen Therapy - UPMC.....	412-647-7480
Immunotherapy - Cancer Research Institute.....	800-992-2623 cancerresearch.org
Mrs. Claus Club of North Hills	412-992-7339 mrsclausclub.org
Nutrition - American Institute for Cancer Research.....	aicr.org
Prostate Cancer Support Group - UPMC.....	412-647-1062
Swallowing Disorders Center UPMC Eye & Ear Institute (Oakland)	412-647-6461 UPMC Shadyside..... 412-621-0123
Young Adult Survivors United	724-719-2273 yasurvivors.org

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.

Head and Neck Oncology

Eye & Ear Institute

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

Head and Neck Cancer Program UPMC Hillman Cancer Center

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

Robert L. Ferris, MD, PhD

Director, UPMC Hillman Cancer Center
Hillman Professor of Oncology
Associate Vice-Chancellor for
Cancer Research
Co-Director, Tumor Microenvironment Center
Professor of Otolaryngology, of Immunology,
and of Radiation Oncology

Christine A. Platania

Head and Neck SPORE
Grant Administrator