

HEADWAY

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

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Examining the prevalence of inadequate health literacy among head and neck cancer patients

By Anna Dainauski, SN, *University of Pittsburgh, School of Nursing, Pittsburgh, PA*; Jonas T. Johnson, MD; Marci Lee Nilsen, Ph.D., RN, *University of Pittsburgh, School of Medicine, Department of Otolaryngology, Pittsburgh, PA*



Anna Dainauski

The Institute of Medicine (IOM) report, *Health Literacy: A Prescription to End Confusion*, defines health literacy as, "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Poor health literacy can make understanding and acting on health information difficult. It has also been shown to negatively affect the ability to follow through with treatment recommendations and can contribute to poor outcomes. It can also influence a patient's ability to make informed decisions about their care. Head and neck cancer patients are often diagnosed with

advanced disease and have to make complicated treatment decisions; therefore, it is important that we understand the range of health literacy in our survivors.

In a study recently conducted here at UPMC's head and neck cancer survivorship clinic, 235 post-treatment head and neck cancer patients were screened for health literacy. They were screened using the Brief Health Literacy Screen (BHLS) – a three-item questionnaire designed to quickly determine a patient's health literacy level. Scores of nine or lower on the screening tool indicate poor health literacy. In this study, 40 of the 235 patients (17% of the population) were found to have poor health literacy. Older survivors were more likely to report lower health literacy scores than younger survivors.

The results of this study show that poor health literacy is common among head and neck cancer patients. The brief health literacy screen is a practical tool for identifying patients with poor health literacy, and it allows providers to better individualize patient education by giving insight into what specific areas of health literacy a patient is having difficulty with. The results of this study were presented at The Eastern Nursing Research Society and Oncology Nursing Society annual meetings.

Healthcare providers can help ensure that patients understand medical information by reducing the use of medical terms and providing instructions that are simple and concise. They can also have patients teach the information back to them. This teach-back technique can help healthcare providers identify issues and clarify information with their patients. Education materials should also be easy to read, which includes large font sizes. Educational material, including videos, can help support patients and help reinforce information. Patients and caregivers can also take a role in protecting their health through active participation in conversations by asking questions and requesting further information when needed. Support groups are another resource that patients can use to become more educated and engaged in their healthcare.

Source: Institute of Medicine (US) Committee on Health Literacy; Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. *Health Literacy: A Prescription to End Confusion*. Washington (DC): National Academies Press (US); 2004. 2, What Is Health Literacy? Available from: <https://www.ncbi.nlm.nih.gov/books/NBK216035/>

Cancer: A 20-year journey

By John S. Nicotra
20 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 the tumor.

Over the span of 20 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.

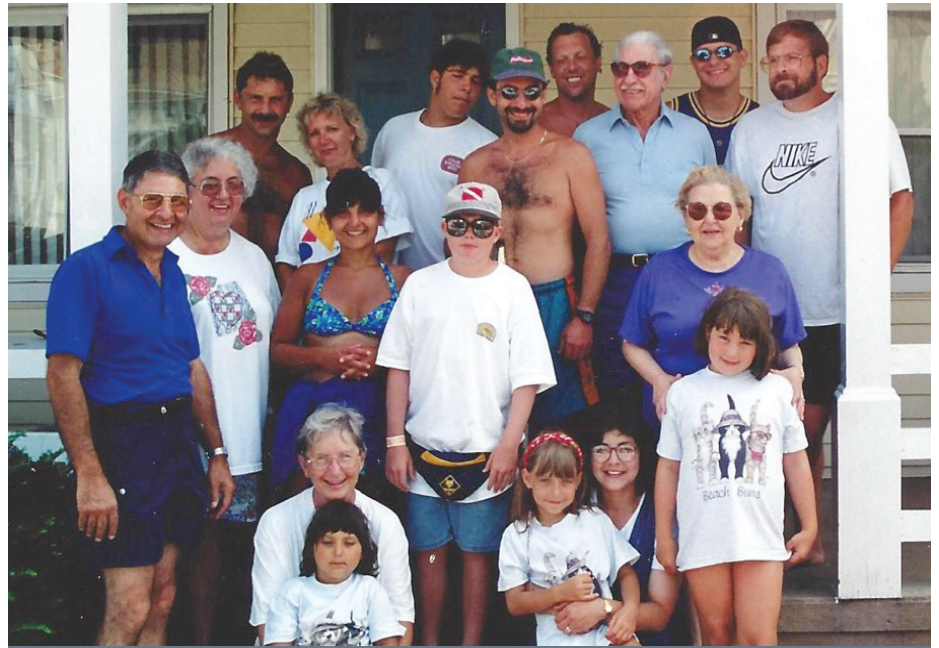
Early on, my wife and I agreed that we would share with our five children any of our serious health issues. Once our doctors verified the potential serious decisions and consequences of our health issues, our children were informed.

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 my 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. My family and close friends have supported my wife and me through all of my 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 my success in overcoming the difficult times I've encountered.



John Nicotra (left) and his family enjoying one of the family vacations in 1998.

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.

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 my 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.



John Nicotra (second row, fourth from the right) with his family at the wedding of his granddaughter Rachel in 2018.

Changes in your thinking? Practical strategies can help

By Rachele Brick, MSOT, OTR/L
University of Pittsburgh, Department of Occupational Therapy



People often experience changes in memory, thinking, and problem-solving skills during and after cancer treatment. While most people experience these

changes during active treatment involving chemotherapy, radiation therapy, and/or hormonal therapies, symptoms may persist up to 10 years after the completion of treatment.¹ Changes in thinking often impact the ability to complete the activities that we need to do, want to do, or are meaningful to us. These activities may include paid or volunteer work; leisure or hobbies; community, social, or civic activities; or interpersonal or relational activities.² Maintaining an active daily routine can help manage these problems. Here are some strategies that may improve management of these symptoms and participation in daily routines.

Maintaining a Routine:

Identify Meaningful Activities: It is important to maintain a daily routine that involves activities that you *must* do (i.e. grocery shopping, paying bills, etc.) as well as activities that you *enjoy* doing (i.e. reading, going out to eat, spectator sports). Participating in a variety of activities has been shown to improve our overall health and quality of life.³ The more we engage in a variety of meaningful activities, the more likely the mind will be challenged to think in new ways and exercise its ability to think! Just as we exercise to improve our physical fitness, participating in a variety of activities can act as exercise for your mind.

Establish a weekly routine: Schedule activities at a consistent time of day or day of the week. The more predictable your schedule, the easier it will be to remember. Try alternating easy tasks with more time-intensive activities. Alternating may provide the mind with a chance to relax and refocus for upcoming activities that need more concentration.

Memory Strategies

For difficult to remember words or phrases, appointments, or daily activities, try using these strategies:

- Keep a list of family and colleague's names and phone numbers at your desk or on the refrigerator.
- Write a checklist each night regarding upcoming daily responsibilities. The checklist acts as a visual reminder of events.
- Use smartphone reminders (i.e. Wunderlist® and Tick Tick®) to remember appointments, meetings, and daily responsibilities.
- Maintain a consistent routine.
- Keep a 'Good Ideas' notebook in your purse or briefcase when you think of upcoming responsibilities out of context.

Thinking Strategies

For challenges with problem-solving, multi-tasking, and concentrating, try using the following strategies:

- Focus on one task at a time - avoid multitasking. For example, rather than paying bills online while talking on the phone, try doing each activity individually.
- Work in a quiet area to avoid distractions. Fewer noise and visual distractions may improve concentration on a task and improve thought processing.
- Use noise-cancelling headphones to eliminate unwanted background noise. For example, allow your mind to focus on reading a magazine without the noise of television or people at work. Our brain must work harder to focus when it has to eliminate unwanted sound.
- Work on difficult tasks when you are most attentive throughout the day. For early risers, this means tackling more complicated work in the morning. Being tired can exaggerate our thinking difficulties, acting like a fog.
- Complete 5-10 minutes of meditation or mindfulness-based activities. Mindfulness activities help to manage stress. Stress can make thinking and problem-solving more challenging as it acts like a distraction to our mind. Relaxation strategies, deep breathing exercises, or listening to calming music may provide the mental clarity needed to tackle more difficult tasks throughout the day.
- Ask family and colleagues for help if a task is becoming too difficult. Family and friends can act as advocates. To save mental energy for a movie or shopping in the mall, ask a friend to drive.

If you have noticed changes in your day-to-day routine due to cognitive changes, a doctor may recommend occupational therapy services to restore engagement in daily activities. Occupational therapy practitioners provide client-centered rehabilitation that can improve performance of meaningful activities and help maintain health.⁴

Rachele Brick is an occupational therapist and pre-doctoral student within the Department of Occupational Therapy at the University of Pittsburgh. She can be contacted at rsb50@pitt.edu.

¹Ahles, T. A., & Root, J. C. (2018). Cognitive effects of cancer and cancer treatments. *Annual Review of Clinical Psychology*, 14, 425-451.

²Sleight, A. (2016). Coping with cancer-related cognitive dysfunction: a scoping review of the literature. *Disability and Rehabilitation*, 38(4), 400-408.

³Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy*, 56(6), 640-649.

⁴Baxter, M. F., Newman, R., Longpré, S. M., & Polo, K. M. (2017). Occupational therapy's role in cancer survivorship as a chronic condition. *American Journal of Occupational Therapy*, 71(3), 7103090010P1-7103090010P7.

Co-survivors: caring for you and your loved one

By Wendy A. Myers, MSW, LCSW
Director of Counseling-Cancer Caring Center
Owner/Clinical Licensed Social Worker-
Find Your Balance, LLC
wendyamyers@gmail.com



If you are helping a loved one get through cancer treatment you are both a co-survivor and a caregiver. Co-survivors can be an adult, teen or child family member

as well as a friend or co-worker. These co-survivors as well as the survivor can have multiple caregiving roles such as caring for children or elderly parents as well as the survivor/co-survivor. It is natural to feel as if you would like to help those individuals that you care about. "Giving Care" means helping with daily needs, helping loved ones cope with feelings and just being present to listen.

While giving care, it is necessary at times put your own needs and feelings aside as the co-survivor. But putting your needs aside for a long period of time is not good for your health. You need to take

Head & neck cancer support groups

- A cancer support group, primarily for head and neck cancer patients, family members, and caregivers meets the first Wednesday of each month at UPMC Cancer Center, Upper St. Clair, 200 Oxford Drive, Suite 500, Bethel Park, Pa. To register, call 412-622-1212.
- **Let's Talk Laryngectomy Support Group** – Meetings are held the first Tuesday of each month at 7:00 pm, Forbes Regional Hospital, 2570 Haymaker Road, Monroeville, Pa. Contact: Rich Boguszewski at rbogos@gmail.com or Dan Evans at djevans222d@gmail.com. <https://LetsTalkGroupPgh.wixsite.com/LaryngectomyHelp>

- Focus on the things that are worth your time – let small stuff go
- Remind yourself that you are doing your best
- Spend time alone to think about your own feelings
- Ask for support with tasks – you do not always have to be the expert
- Allow teens/children to help out – good for them to feel they are contributing

“How well people manage their lives marked by illness depends not on the nature of the illness, but on the strength of their conviction that life is worth living no matter what complications are imposed on it.” –Cheri Register, *Living with Chronic Illness: Days of Patience and Passion*.

Head and neck cancer patient survivorship symposium

2018 Symposium: Survivorship of the Head and Neck Cancer Patient was held on August 6-7, 2018 and was attended by 111 registrants from across the United States and Canada. Survivorship has been defined as the provision of enhanced coordination of care for people with the diagnosis of cancer. Physicians have been long aware of the importance of surveillance to detect recurrent cancers and encourage prevention to avoid the development of second tumors. Today we employ patient reported outcomes (PRO's) to enhance understanding of side effects that develop after cancer and its treatment. A coordinated approach to the treatment of these side effects has been deemed essential.

PRO's we have collected from over 600 individuals indicate that approximately

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care of you too! If you don't you may not be able to sustain the marathon of caring for someone through a cancer diagnosis. A simple example is given when you are flying in an airplane and the stewardess instructs you to FIRST put on your own oxygen mask and THEN the others that need help around you.

The cancer journey is like a roller coaster, each family seeking to navigate through four areas:

- **Fear/Anxiety/Worry** – with support leads to establishing – *Courage*
- **Lack of Control** – with empowerment learning self-advocacy leads to – *Acceptance of Continual Change*
- **Hopelessness** – with encouragement and a mutually agreed upon treatment plan leads to – *Hope*
- **Sadness** – with emphasis on living each day to the fullest leads to – *Joy*

Both survivors and co-survivors experience a wide array of feelings throughout this journey – sadness, anger, guilt, grief and loneliness. Co-Survivors can help deal with these feelings and seek to conquer the four areas listed above by accompanying your loved one to medical visits, talking with the health care providers and asking your loved one to be your guide by letting them tell you what their needs are and in return for you also to express your needs to best support them.

Some co-survivors will experience feelings of guilt for becoming frustrated with caregiving. This can lead to not taking care of themselves which results in Compassion Fatigue. Compassion Fatigue is characterized by physical and emotional exhaustion and a profound decrease in the ability to empathize. It is a form of secondary traumatic stress. This stress occurs as a result of helping or wanting to help those who are in need.

Co-Survivors can fall into 2 categories:

- Those who act out of pity and sorrow lead to sympathy which can result in

ignoring their own needs, putting themselves at risk for Compassion Fatigue.

- Those who act out of compassion and recognize the importance of caring for themselves as well as caring for others are more driven by empathy, which is the ability to understand and share the feelings of another. Although most of us experience sympathy for others in need, when combined with empathy it will ensure that both the survivor and the co-survivors needs are met.

Tips for the co-survivor:

- **Make time for yourself – time off, join a group/talk with a counselor, be nice to yourself**
- **Find meaning during your cancer journey – look at life in a new way, find purpose/value**
- **Educate yourself about Compassion Fatigue – seek support**
- **Set emotional boundaries**
- **Find outside hobbies**
- **Keep a gratitude journal**
- **Learn resilience**
- **Know we all make mistakes – no one is perfect**
- **Cry or express your feelings – find help with managing family conflicts that may occur**



Symposium attendees included (from left): Dr. Jonas Johnson, Bonnie Martin Harris, Anna and John Albrecht, Karen Losego, Tami Wasserman-Wincko and Marci Nilsen (co-chairman).

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 twentieth anniversary of first being diagnosed with squamous cell carcinoma of the cheek. My next thought was "Holy heck 20 years! He must be Doctor Johnson's oldest living patient!"

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.



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

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. Doctor 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 Doctor 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 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 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 outpatient surgeries for recurrences, more family vacations, Easter egg hunts, golf outings, and enjoying life, my dad is 80 years old. Many people didn't think dad would see 80 years old. It did look grim for a while. Our family has lost a few close

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For additional topics on the prevention, detection and treatment of cancer, including head and neck cancer, visit http://www.upmc.com/portal_headneck/publications.cfm for archived issues of *Headway*.

Cancer affects the entire family: a daughter's perspective

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family members, some much younger than dad, yet he is still here. And there is a reason. Last year mom, the matriarch of the family, was diagnosed with liver cancer and passed away months later. 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.

Survivorship symposium

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90% of survivors of head and neck cancer have side effects that interfere with their daily lives. The most prevalent side effects include: difficulty swallowing, dry mouth, pain and abnormal ability to chew. Over half of the patients have three or more residual problems.

Keynote speakers at the symposium discussed each of these problems. Panel discussions explored opportunities to further assist in recovery from cancer. The panels were informed by participation of several patients who were able to give firsthand witness to the realities of these challenges.

Special topics included a report on the frequency of hearing loss. Poor hearing has an impact on medical as well as social implications. Fighting cancer is associated with anxiety and depression. Helping people find help is a priority. Additionally, the long term need for health care can be expensive or even toxic.

Enhanced awareness of treatment related toxicities and side effects offers the opportunity to seek new ways to avoid these toxicities. Early recognition provides the potential for enhanced recovery while recognition of the chronicity of treatment related side effects further encourages the need for lifelong support.

Contact information

American Cancer Society.....	1-800-227-2345
Assistance with Coping.....	412-623-5888
Cancer Caring Center.....	412-622-1212
Cancer Information and Referral Services.....	412-647-2811
Clinical Trials.....	412-864-1728 or 412-864-3759
Eye & Ear Foundation.....	412-383-8756
Face2Face Healing.....	1-844-323-4325
Family Care Giver Education and Support.....	412-623-2867
Gumberg Family Library.....	412-623-4733
Head and Neck Cancer Support Group.....	412-622-1212
Heart and Hands Ministry.....	724-935-3636
Hopwood Library at UPMC Shadyside.....	412-623-2620
Hyperbaric Oxygen Treatment.....	412-647-7480
Our Clubhouse.....	412-338-1919
Pain and Supportive Care.....	412-692-4724
Prostate Cancer Support Group.....	412-647-1062
Satchels of Caring Foundation.....	412-841-1289
Swallowing Disorders Center	
UPMC Eye & Ear Institute (Oakland).....	412-647-6461
UPMC Shadyside.....	412-621-0123
UPMC Division of Sleep Surgery	
Mercy.....	412-232-3687
Monroeville.....	412-374-1260
American Cancer Society website.....	www.cancer.org
Head and Neck Cancer	
Program website.....	UPMCHillman.com/headandneck

Head and Neck Cancer Program website

Looking for more information about patient services, current research, clinical trials, news and events, and other valuable information pertaining to head and neck cancers? Check out the website for the Head and Neck Program of UPMC Hillman Cancer Center at UPMCHillman.com/headandneck.

Clinical trials

For more information about head and neck clinical trials, contact Amy at 412-864-1728 or Denise at 412-864-3759.

Head and Neck Oncology

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