Health Care Advocates and Patient Navigators
Who They Are and What They Do
Elisabeth Schuler Russell

What is the history of patient navigation?
You may have come across the terms "patient navigator" or "patient advocate" in the last few years and wondered what they mean. Patient navigation or patient advocacy is an emerging profession that is gaining attention, both in the media and in the popular lexicon, because it fills so many gaps in the current American health care system.

The original concept of patient navigation was pioneered in 1990 by Dr. Harold P. Freeman, a surgical oncologist at Harlem Hospital, for the purpose of eliminating barriers to timely cancer screening, diagnosis, treatment, and supportive care. Many individuals in medically underserved or minority communities were at risk because of financial, communication, health care system, and cultural barriers to care.

Dr. Freeman's Patient Navigation model represents a community-based support program designed to eliminate barriers to early diagnosis and treatment of cancer. Currently, his model has been expanded to include the timely movement of an individual across the entire health care continuum from prevention, detection, diagnosis, treatment, and supportive, to end-of-life care.

In 2006, U.S. policymakers came together to support the Patient Navigator Outreach and Chronic Disease Prevention Act of 2006 (Public Law 109-18). With unanimous support in Congress, and under the leadership of Senator Robert Menendez (D-NJ), the Act authorized the Secretary of Health and Human Services to make grants through 2010 for the development of patient navigator programs. A total of $25 million was awarded over five years.

Over the years, data from Dr. Freeman's programs and others began to prove how valuable navigation could be to improve cancer diagnosis and treatment outcomes. Studies found that patient five-year survival rates went from 39% (prior to the development of the patient navigator program) to 70% for breast cancer patients at Harlem Hospital.

Research has shown that patient navigator interventions produce greater rates of screening and follow-up on diagnosis, resulting in better health outcomes. For example, in a study on colorectal cancer screening within a large urban hospital, two patient navigators were hired for a study period. Broken appointment rates went from 67% to 5% in one month. Another colorectal cancer screening study within a minority community health setting compared two groups of patients with similar demographic characteristics who were recommended colonoscopy services by their physicians. The patients from the navigator-assisted group had a 15.8% compliance rate, compared with only 5% in the non-navigator-assisted group.

What are private patient advocates and navigators?
Even as the U.S. Government has begun to address the disparities in access to cancer care among specific communities and populations in the past five years, the idea of private, one-to-one patient advocacy was born of necessity as a way to mitigate the complicated, inefficient, expensive, and fragmented health care delivery system in the United States. My story provides a good illustration. You may be wondering how my practice ended up with the name Patient Navigator since I am not associated with Dr. Freeman. My journey through the complexities of the American medical system began in 1998, when our 2-year old daughter was diagnosed with a fatal, inoperable brainstem tumor. We were immediately forced to make life-and-death decisions during a time of intense fear and vulnerability, with no experience upon which to draw.

Over the ensuing years, as our daughter recovered and remained healthy, I realized how much I had learned and I wanted to share that information. I believed deeply that no family should be cast into such dire circumstances as we were without a lifeline or a guide. During a conversation with my pastor in 2003, I asked him, "What can I do to thank God for the miracle of my daughter’s survival?" He told me, very simply, "You should help other people going through the same thing."

In 2003, I was still fully employed in my first career, as a Foreign Service Officer with the Department of State. It was during a lunchtime walk with a colleague that I came up with the name for what I wanted to do: navigate patients through the health care system. Interestingly, in 2003, I had never heard of Dr. Freeman. I only knew that I wanted to advocate, educate, and solve problems for patients and families in the American health care system, to help them find the way to the right diagnosis, doctors and decisions. You can read more about my story in the March 2011 issue of "MORE Magazine" and the "Vienna Connection". I officially launched Patient Navigator, LLC in October 2004, and am often called a "pioneer" in this field. Since then, the
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concept of patient advocacy has taken on a life of its own. More people are learning that they can hire an advocate or navigator to help them with their medical problems, much as people now seek out personal trainers, life coaches or other “guides.”

In August 2009, the National Association of Healthcare Advocacy Consultants (NAHAC) (www.nahac.com) was created by Joanna Smith, owner of Healthcare Liaison, in Berkeley, California because it made sense to form a professional association for this new type of work. I am a founding member of NAHAC and was elected as its first Vice President, a position I still hold. The Association seeks to professionalize the emerging private patient advocate industry and to educate consumers. Members must abide by our Code of Ethics. The Association held national conferences in 2009 and 2010; our third meeting will be in November 2011. As with any infant industry, there is a lot of experimentation that goes into charting new territory. But it should reassure consumers that as the need for advocacy services grows, they will have a reliable way to find and screen patient navigators and advocates.

What kinds of things do patient navigators or advocates do?

Private patient navigators and advocates in most cases work directly with and are paid by individuals and families. Private advocacy or navigation services are not covered by insurance, despite the fact that many studies prove that better coordination of medical care saves money and improves outcomes.

The names for this work may vary (patient advocate, navigator, health care advocate or consultant, medical advocate) but the basic idea is the same. We work with patients and families to help them at many points along the health care continuum: disease research, insurance problems, finding doctors, understanding treatment and care options, accompanying them to visits, serving as coach and quarterback of their health care team, working with family members and caregivers, mobilizing resources, managing medical paperwork and almost anything else you can think of. Not every advocate does all of these things, and there is no single business model or list of services. Some advocates only work with senior citizens, others only with cancer patients or others only to solve medical billing problems. It depends entirely on the individual’s business and practice.

There are now also more hospital-based nurse navigators, particularly for breast cancer patients. Because breast cancer activists raise a great deal of money each year, these organizations often fund nurse navigator positions in hospitals. In most cases, these hospital-based navigators primarily manage the patient's needs during the hospital stay and discharge planning and they work for the hospital. This is in contrast with private navigators, who work for their client and stay with them well beyond a hospital visit.

There is at least one very large health advocacy company, founded by former insurance executives, that sells its services to corporations and organizations who then offer advocacy services (help with insurance claims, for example) as an employee benefit.

Who are these private advocates and navigators?

Once again, there is no single definition or job description. In the past few years, I have been contacted by hundreds of people seeking my advice on how to become a patient navigator. The majority of people (mostly women) who want to do this work come to it because they have been through a life-changing medical event, either for themselves, a friend, or a loved one. Some have been through cancer treatments, some have been through heart surgeries or organ transplants, some have been through intensive care unit stays where the patient was comatose for weeks, and others have been through research studies that involved many, many visits to the hospital.

It depends entirely on the individual's business and practice.
PATIENT NAVIGATOR, from page 2

one. They have learned the hard way how difficult it is to navigate and manage a complicated diagnosis, treatment, or chronic condition. Their eyes have been opened to the confusion, lack of coordination, dangers, and inefficiencies in our health care delivery system and now they want to share both what they have learned and how to avoid missteps along the way. In the majority of cases, these are laypeople with no prior medical experience or training.

While hospitals will generally only hire nurses or other medically licensed professionals as their in-house navigators, most private advocates are not medical professionals but come from a variety of backgrounds.

There is a growing number of nurses, doctors, and other medically trained professionals who are now also becoming private patient advocates. In addition, career-changers are considering advocacy as a second career. These are women or men who have long-established careers in other fields, but decide that they want to do something that they see as more meaningful, often because of a personal experience.

Most of us who do this work come to it through our own experiences dealing with the health care or elder care system (whether as a patient, caregiver, nurse, social worker, etc.) There is no specific background or education that is required. I have found that a passion for helping others, good research, communication, interpersonal and organizational skills, as well as the ability to creatively find resources and solve problems are needed to be a good navigator.

What credentials or degrees are needed to be a patient advocate? There is one very important point to emphasize here. Patient advocacy/navigation is a new and emerging profession, still defining itself. This is not a regulated industry. There is no national or state licensure. There is no nationally recognized credential for calling yourself a patient advocate or navigator.

This becomes important because as more people want to become patient advocates, a growing number of training and certification programs have been created. There are now close to two dozen educational organizations running workshops, webinars courses, and programs that culminate in some type of certificate. However, this only means that their participants have completed a program. It does NOT mean that a person is nationally certified in anything. So if you are a patient or caregiver, don't be fooled into thinking that just because someone has completed one of these programs, that they are recognized to have met any standardized set of criteria. If an advocate claims to be certified, ask about it to be sure you are clear on what they have achieved.

How can I find a navigator or advocate? The National Association of Healthcare Advocacy Consultants (www.nahac.com) offers a searchable directory of members on its website. Another directory is available through AdvoConnection (www.advoconnection.com). Word of mouth or personal referrals are always a good way to find a navigator as well.

What questions should I ask if I want to hire someone? What should I expect? What do they charge? You should interview an advocate or navigator the same way you would interview any other professional you would consider hiring. Among questions you could ask are: Have you handled other cases similar to mine before? What is your background and training? How long will it take to perform the services I need? What do you charge? Do you have references? Do you provide written reports about the services you have provided? Where are you located? What are your hours? How do you communicate with your clients? What would you typically do to help someone in my situation?

Working with a patient navigator is an intensely personal relationship. You must feel that you can trust and work with that person comfortably. You should expect that the navigator will respect your privacy and that he or she is a good communicator. You may need to speak with several candidates before you feel comfortable moving ahead.

You should also expect a written contract or agreement which specifies what the navigator will deliver to you and when, as well as a detailed explanation of his or her fees and charges. Do not rely on verbal promises or commitments; get it in writing.

There is no standard fee for private navigation services. Fees can range from $60 to $250 per hour, depending on the person you interview. Based on the navigator’s track record, you should feel comfortable that you will be getting your money’s worth, as you would with any other professional service provider.

Will health care reforms make advocates available to people? The new health care law passed in 2010 contains pilot Medicare projects to improve care coordination and efficiency. The idea of a “patient-centered medical home” may also affect how services are delivered in the future. There is no provision at this time that would cover the cost of private navigators or advocates, but if these pilot programs are successful at reducing costs and improving efficiencies and outcomes, both insurance companies and policymakers may begin to see the value in paying for navigators to coordinate care.

For example, in a fascinating 2009 study that quantified the costs to our health care system of uncoordinated care, the data illustrates clearly how care coordination can help to reduce costs to the health care system. This is already what patient navigators do: we help patients integrate and coordinate their care, improve compliance and avoid duplicative or unnecessary interventions, among other things.

For a Medicaid only group that was analyzed, uncoordinated care patients represented less than 10% of patients yet accounted for an average of 46% of drug costs, 32% of medical costs, and 36% of total costs for the population. The vast majority of identified uncoordinated care patients had at least one chronic condition. Uncoordinated care patients had average annual total costs of $15,100 vs. $3,116 for those with better-coordinated care in the remaining population.

For the Medicaid subset of patients aged 55-64, those exhibiting patterns of extreme uncoordinated care represented about 28% of patients, yet accounted for a very large percentage of costs (52%). One of the study’s conclusions, based on multiple analyses, is that an average of 35% of the costs contributed by patients with extremely uncoordinated care should be avoidable with improved efforts of care integration, enhanced and targeted interventions, and coordination of care between providers. That’s what navigators do.

Editor’s Note: Elisabeth Russell is the Founder of Patient Navigator LLC, a company established in 2004 to help patients and families navigate illness and the U.S. healthcare system. She is also the Vice President of the National Association of Healthcare Advocacy Consultants. For more information, please visit www.patientnavigator.com and www.patientnavigator.com/blog
A TIME FOR SHARING...Gin Sanders Gives Back

Thanksgiving is a time for reflecting on the many blessings that are bestowed upon us. Sometime just before Thanksgiving 2010, Gin Sanders, a head and neck cancer survivor, contacted SPOHNC. Gin and her husband “Satch” were putting together a fundraiser for the benefit of the Head and Neck Cancer Research Program at the Dana-Farber Cancer Institute in Boston, MA.

Gin, a five year survivor knew what she had to do; She had made 3 promises to herself in the past, and her third promise was to host a Gala fundraising event, with her husband Tom “Satch” Sanders, a prostate cancer survivor. This Gala Sneaker Ball was to honor those who have dedicated their lives to oral, head & neck cancer. Consequently, the Gin and Satch Sanders Gala Sneaker Ball Award Selection committee chose Marshall Posner, MD, as the “Physician of Excellence” and Nancy Leupold, President and Founder of SPOHNC, was selected to be the first recipient of the Head and Neck Cancer Hall of Fame “Patient of Achievement” award. Warren Perry was posthumously honored with the “Patient of Courage” award.

All of us here at SPOHNC were very moved and proud of Nancy. We felt that they had chosen the best candidate. What better way of honoring our Founder & President for all of her hard work, dedication and commitment to the head and neck cancer community?

Nancy is one of those individuals you are lucky to meet in a lifetime. She embodies empowerment, strength and a compassion that we look to find in today’s society. She is generous and gracious, having given her life to this organization since its inception. Without her giving personality, SPOHNC could not have reached its milestone of “twenty years” this year.

The “Gala Sneaker Ball” was held on April 15th in Boston and it was a tremendous hit. Everyone invited to the Ball was asked to sport bedazzled sneakers for the theme of the evening, to compliment their tuxedos and beautiful ball gowns. Many wore low top sneakers and then there were some with hi-top versions; even those with high heels! We decided to adorn my hi-top sneakers with the colors of our organization, SPOHNC and Head and Neck Cancer. Everyone searched tirelessly for gems that were burgundy and ivory. The ivory, of course, happened to reflect a pearl, which was a stunning addition to my sneakers. With the assistance of my colleague, Chris Leonardis, who is very adept with a glue gun, we created one-of-a-kind sneakers that included our SPOHNC logo.

At the Gala, an array of wonderful prizes were presented for everyone to bid on. All proceeds would go to funding important research for head and neck cancer at the Dana-Farber Cancer Institute. Proceeds from one of the prizes went to SPOHNC, to support our programs and services. Mistress and Master of Ceremonies included Fox 25 News Anchor Maria Stephanos, (who also happens to be Gin’s daughter-in-law) and Sports Entrepreneur Butch Stearns. There were even some famous basketball players among us, as Satch was accompanied by Boston Celtics teammates who supported him and Gin in their fundraising efforts. Music and entertainment was provided by “Deadbeats”, whose drummer, Joe Pulitano is a survivor of head and neck cancer. Guests dined on fabulous food, and danced the night away – in their sneakers!

Nancy’s excitement was contagious. To be honored at such a prestigious event amongst her peers and share the evening with her family and friends was a night to remember. Nancy exemplifies the spirit of one who was confronted with a disease, battled that disease, and then sought to help others who were going through a similar journey.

All of us will continue with her vision of raising awareness, and supporting those who have been diagnosed with this disease. We continue to seek out invaluable information, and through everyone’s efforts, SPOHNC is able to do this. SPOHNC and its members are a community of exceptional people doing great things to make a difference. Let’s continue to do what Nancy started by saluting all of her efforts, and congratulating her on a job well done! Yes, we are thankful for her vision and the direction she sought and what she has achieved.

Mary Ann Caputo
Executive Director, SPOHNC

CORRECTION
From the May 2011 Issue
The correct e-mail address for Jeff Kopito
jkopito@webax.com
Speaking Up to Save a Voice: New Surgery Creates a Vocal Platform

Jerry Young had a routine endoscopy and assumed that the hoarseness that appeared in his voice was an after-effect of that exam. “If it doesn’t go away in a couple of weeks, make an appointment with an ENT,” his doctor told him. It didn’t and Young went to see an ear, nose and throat physician, who thought the redness on Young’s left vocal cord was caused by a virus.

Young was not convinced. He had been retired from his job as an engineer and yet his information-seeking mindset continued. His research made him suspect that cancer was the cause. A friend of his wife, under treatment for cancer at Stanford Hospital & Clinics, recommended he see a physician there.

His redness was cancer, a squamous cell carcinoma. It was small, at a very early stage. Radiation offered as much as a 90 percent chance of removing the cancer, so Young went through that treatment. But the cancer remained and Edward J. Damrose, MD, director of the Stanford Voice and Swallowing Center, became Young’s doctor.

In the midst of his fear about the cancer, Young prepared himself for the worst. He didn’t think about what surgery might bring; he just wanted the cancer out. “Both my mother and brother died young, of pancreatic cancer. I knew mine was neither as aggressive nor lethal as theirs, but having any kind of cancer was not something I wanted,” he said.

More than sound
He did trust Damrose’s knowledge. “I had a lot of confidence in Dr. Damrose, in him as a person and his ability to make good decisions,” Young said.

What Damrose did was a surgery that saved Young’s ability to speak without any kind of mechanical equipment inserted in his neck, preserving his dignity and freedom of expression. In a surgery done only at a couple of medical centers in the U.S., Damrose removed the part of Young’s larynx where the cancer lay. Then he closed the gap by connecting the two main supports of the larynx, the cricoid cartilage and the hyoid bone. Instead of air vibrating through the muscular vocal cords, it vibrates with the help of cartilage, allowing a human voice instead of a robotic one to say the words that form Young’s life. The procedure is called a supracricoid laryngectomy with cricohyoidoepiglottopexy. Young’s surgery was one of just a dozen times in the last year that Damrose, one of the nation’s few experts in the procedure, performed at Stanford Hospital & Clinics.

The voice is, of course, as distinctly identifying as a person’s face. Perhaps even more than the face, the voice is a nuanced audio track of every possible emotion. From the interplay of the vocal folds, muscles, cartilages, nerves, tongue, mouth, palate and lungs comes the ability to form words that resonate and emerge as audible communication.

The ability to speak can be altered by a number of changes in that set of voice-enabling components, including loss of muscle mass, decreased saliva and vocal cord atrophy or paralysis. And, surgery for cancer.

The traditional approach has been to remove the entire larynx, following failed chemotherapy or radiation. It’s a relatively quick surgery - about four hours, compared to the seven hours Damrose needed for Young’s partial laryngectomy. The impact is hugely different. With a total removal of the larynx, speaking is possible only with external help.

The most common involves a prosthesis that fits into a hole in the throat; some work when pressure is applied, others can function hands-free. For others, speaking requires an electronic device pressed against the throat to amplify vocal sounds. Sometimes, some of the nerves to the tongue can be affected, damaging the ability to swallow and taste.

Challenging Circumstances
Cancer of the larynx is the most commonly diagnosed head and neck cancer. Between 10,000 and 12,000 new cases emerge each year in the United States. But it is the least common cause of hoarseness. Its symptoms also include difficulty swallowing, coughing up blood, sore throat and trouble breathing.

Any surgery in these tight quarters must be done precisely. “One millimeter too far one way,” Damrose said, “and you’ve cut out an important nerve needed to speak. Too far the other way and you’ve left cancer behind, or your patient will never swallow again.”

Advancing options
The psychological trauma, Young said, is immense. He saw it first when he went to a meeting of a laryngectomy support group and found himself the only person without a prosthesis. “None of the people there had ever even heard about the surgery I’d had.”

Developed in the 1950s and popularized by French surgeons, the surgery Damrose performed on Young was not done in the U.S. until the 1990s. Damrose describes the approach as elegant. “It was hard to visualize why it should work,” he said, “but once you look at what you’ve got, it becomes very intuitive as to why it works and works so well.”

Yet its frequency remains low. The most recent data shows that in patients who fail radiation, up to 50 percent may be candidates for the voice-preserving partial laryngectomy.

Damrose trained with that physician and with the physician who did the first U.S. surgery. Now, he is training others. “I’d like to see this more routinely offered, to preserve more larynxes,” he said. “It’s an operation that has a high degree of success and predictable results. It’s worthwhile trying.”

Young is an example of someone whose cancer was caught early, “otherwise a healthy, vibrant, vital guy who can now look forward to years of quality voicing,” Damrose said.
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Support Your Partner Through Cancer

Many couples today face the challenge of battling cancer together. "Cancer not only affects those diagnosed, but also the partners who love and care for them," says Robert Miller, MD, radiation oncologist at Wellspring Oncology in Pinellas Park, FL. "Thousands of people are diagnosed with cancer every day, and thousands more step into a new supportive role."

However, there is no handbook to guide those in taking on this supportive position, leaving many spouses feeling frustrated and confused. "For many people living with cancer, support from their spouse is extremely important in helping them battle the disease," says Dr. Miller. "Often, however, partners feel unsure of the best way to offer that support. They know that they want to support their spouse, but they just aren't quite sure how to go about it."

How, then, does one face this role head-on and help the one they love most in their fight against cancer? Dr. Miller offers some advice to help spouses provide the support their partners need.

Communication Is Key
One of the best ways to offer support to your partner is through communication. Discuss what you are both thinking and feeling on a regular basis, and allow your spouse to talk for as long as he or she needs. Also, encourage your partner to express his or her true feelings, both good and bad. Understanding your spouse's thoughts and emotions is key to supporting them.

"It's so important that a couple communicate with one another during such a difficult time," says Dr. Miller. "In order to effectively support your partner, you have to know what he or she needs from you. There's no better way to find out than to ask."

Dr. Miller also reminds supporting partners that these needs may change often. For those living with cancer, emotions and the needs that come with them can differ from one day to the next, so being in tune with those is essential to providing the best support you can.

Let Them Decide
During this journey, your spouse may have to make some difficult decisions regarding his or her health. Be supportive of these decisions, even if they aren't the ones you may have made. While the two of you are on this journey, it's important to remember that it's your partner who is living with the disease. Offer your input and discuss your fears, but allow your spouse to decide what he or she thinks is the best choice.

Don't Forget Yourself
The best way to make sure you have the physical and emotional ability to continue caring for the one you love is by keeping yourself healthy. When your partner is living with cancer, it can be difficult to focus on your own needs. However, it's important to remember self-care, as well. Taking a moment away will not only allow you time to focus on yourself, it will also make you a better caregiver for your spouse. "It's common to spend less time on yourself when you're caring for a spouse with cancer," says Dr. Miller, "but if you don't take care of yourself, it will be much more difficult to care for your partner. Taking time for yourself will be beneficial for both of you."

So spend a little time on yourself. Take short breaks and do something active, like going for a walk or spending an hour at the gym, and try to maintain a healthy diet as well. Exercise and eating well may seem like the least of your worries, but it's important for the well-being of both you and your spouse.

Remember Your Relationship
Even though you've taken on this new supportive role, it's important to remember that you are also a spouse. While your partner may need a caregiver, he or she also needs that relationship that was there before the cancer diagnosis.

"It's easy to get caught up in the caregiver role, but don't forget to also be a spouse," says Dr. Miller. "Even during such a difficult time, couples should still continue being couples."

So spend some time together focusing on one another, not cancer. If your partner is feeling well enough, go out for a date night. Or if your spouse isn't feeling up to a night out, just enjoy time with one another at home. No matter how you go about it, spend time together as a couple and continue to be a spouse to your partner.

Living with cancer can be one of the most difficult times a couple can face. However, as a partner, you have the ability to give the support, love, and encouragement that your spouse needs the most to battle this disease.

Spend some time together focusing on one another, not cancer

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ORAL, HEAD AND NECK CANCER NEWS
First Genetic Variations Pinpointed in Head and Neck Cancer

Findings published in Science expected to move treatment toward a more customized approach

July 28, 2011 HOUSTON — The first comprehensive studies of genetic variation in head and neck squamous cell cancers have uncovered mutations that may help refine treatment for patients with the disease, according to researchers at The University of Texas MD Anderson Cancer Center.

The two multi-institutional studies, both published online on the Science Express feature of the journal Science, found:

• Mutations that affect an unexpected tumor-suppressing role of the NOTCH1 gene;
• Infrequent but significant mutations in four suspected cancer-causing genes; and
• Frequent mutation of the tumor-suppressing gene p53, which previously was known to be damaged or impaired in head and neck cancer.

“These findings should help us better treat patients by allowing us to take a more personalized approach than is currently possible with this cancer,” said Jeffrey Myers, M.D., Ph.D., professor in MD Anderson’s Department of Head and Neck Surgery and co-senior author of one of the papers.

“Long term, we’ll see how patients with these genetic mutations do with our conventional treatments of surgery, radiation, chemotherapy or chemoradiation,” Myers said. “This will help us identify groups of patients who need additional or different treatments. Also, some of the newly identified mutations might prove to be potential targets for treatment.”

“In the near term, we found mutations that increased expression of PI3K, which is known to be an oncogene in other cancers. There are drugs being studied that target the PI3K pathway, so we might be able to select patients who could benefit from clinical trials of these promising agents,” Myers said.

MD Anderson scientists teamed with others from Baylor College of Medicine (BCM) and the Johns Hopkins Kimmel Cancer Center to analyze 32 head and neck tumors. They then validated their findings in another 88 tumor samples. A separate team of researchers from the Broad Institute, Dana-Farber Cancer Institute and the University of Pittsburgh School of Medicine reached the same conclusions based on the analysis of 74 tumors.

About half of head and neck squamous cell cancer patients survive for five years after diagnosis. Disease treatment can disfigure and/or impair breathing, swallowing, speech, taste, hearing or smell. Each year about 50,000 new cases are diagnosed in the United States compared to about 500,000 worldwide.

Prime risk factors for the disease are tobacco and alcohol use, and infection with high-risk subtypes of the human papillomavirus, Myers said. In India, Taiwan and other Asian nations chewing betel or areca nuts also raises the risk of developing oral cancers.

Mutations less common in oncogenes
The researchers found that the tumor-suppressing gene TP53 was mutated in 47 percent of the tumors, by far the most commonly affected gene. So far, attempts to restore normal expression of the p53 protein, and expression of other impaired tumor-suppressors, have largely been unsuccessful.

“However, the finding from an unbiased approach that p53 mutation is the most common genetic abnormality in head and neck tumors indicates that we have to keep working with p53 to determine how it can be best used as a biomarker and/or therapeutic target,” Myers said.

Next most common was NOTCH1, which was altered in 15 percent of tumor samples. Previously found to be an oncogene in leukemia, the team’s findings pointed to a tumor-suppressive role for NOTCH1 in head and neck cancer. The researchers are following up to sort out the gene’s role.

“NOTCH1 plays a dual role in biology, maintaining stem cells in some tissues or causing them to terminally differentiate in other tissues. This might explain why it could be an oncogene in one context or a tumor-suppressor in another,” said Mitchell Frederick, Ph.D., assistant professor in Head and Neck Surgery and co-lead author of the paper.

Newer, targeted cancer therapies typically aim to shut down expression of oncogenes, mutated or dysregulated genes that fuel cancer growth and survival. PI3K (6 percent of tumors) and HRAS (4 percent) were the most commonly mutated oncogenes identified by the two groups.

The team also found infrequent but significant alterations in the tumor-suppressors CDKN2A (9 percent) and FBXW7 (5 percent).

HPV-driven tumors are genetically simpler
Human papillomavirus (HPV) is a recently recognized risk factor for head and neck cancer. Research has shown that patients with HPV-associated cancer have longer overall and progression-free survival.

The team found a possible explanation for that: HPV-associated cancers had fewer mutations per tumor (4.8 plus or minus 3) compared to tumors not related to the virus (20.6 plus or minus 16.7). And none of the HPV-associated tumors harbored mutations in TP53.

Patients who used tobacco had more than twice the number of mutations per tumor as those who did not.

The researchers conclude that prevention, risk assessment and early detection of head and neck cancer remain the best ways to reduce illness and death from the disease.

Next: A more comprehensive look at genomic activity
Myers said the genetic variation analysis is part of a larger study under way that will include additional genomic aberrations found in the tumors – gene copy number alterations, expression of messenger RNA and microRNA, and the epigenetic silencing of genes by methylation.

“We hope that by integrating these different types of genomic alterations, we can better understand how they work together and how they affect disease progression,” said co-lead author Curtis Pickering, Ph.D., a post-doctoral fellow in MD Anderson’s TRIUMPH (Translational Research in Multidisciplinary Programs) program.
CHAPTERS OF SPOHNC

SPOHNC P.O. Box 53 Locust Valley, NY 11560-0053 1-800-377-0928

IL-EVANSTON/HIGHLAND PARK
North Shore University Health System
Call for location
2nd Monday: 6:00-8:00 PM
Sabina Omercajic, MS, CCRP 847-570-1066
somercajic@northshore.org

IOWA-DES MOINES
Iowa Methodist Medical Center
Suite 450
1st Wednesday: 5:30 PM
Jennifer Witt, RN, MSN, OCN
wittjl@ihsm.org

KANSAS-KANSAS CITY
Univ. of Kansas Hospital
2nd & 4th Wednesdays: 4:00-5:00 PM
Mary Moody, LMSW 913-588-3630
mmoody@kumc.edu

LOUISIANA-BATON ROUGE
Cancer Services of Greater Baton Rouge
3rd Wednesday: 4:00 PM
Ester Sachse 225-927-2273

MAINE-AUGUSTA/CENTRAL
Harold Alfond Center for Cancer Care
Therese Berniger, SLP-CCC, SLP-CCC 207-872-4051
therese.berniger@mainegeneral.org

MARYLAND-BALTIMORE-GBCM
Milton J. Dance Head & Neck Center
Physicians Pavilion East Conf. Ctr.
3rd Tuesday: 7:00 PM
Dorothy Gold, LCSW-C, OCN 443-849-2980
golddg@gbcmc.org

MARYLAND-BALTIMORE-JHMI
Johns Hopkins – Greenspring Station
2nd Wednesday: 7:00-8:30 PM
Kim Webster 410-955-1176
Kwebster@jhmi.edu

MASSACHUSETTS-BOSTON
Massachusetts General Hospital,
One Tuesday every other month: 6:00-8:00 PM
Valerie Hope Goldstein 617-726-0651
vgoldstein@partners.org

MASSACHUSETTS-CAPE COD
Falmouth Hosp-Clark Cancer Center
Rad/One Conference Room
3rd Thursday: 2:00-3:30 PM
Jeffrey A. Gaudet, LICSW, OSW-C 508-862-7571
jgaudet@capecodhealth.org

MASSACHUSETTS-DANVERS
MGH Northshore Cancer Ctr.
2nd Tuesday: 5:30-6:30 PM
Mary Anne Macaulay, LCSW 978-882-6002
mmacaulay@partners.org

MICHIGAN-DETROIT
Henry Ford Hospital
Josephine Ford Cancer Center Ctr. Rm. 2083D
1st Wednesday: 11:30 AM
Amy Orwig, MSW 313-916-7578
aorwig1@hfhs.org

MICHIGAN-TROY
Beaumont Health Cancer Center
Wilson Cancer Resource Center
4th Thursday: 6:30 PM
Carrie Erikson, LCSW, LSW 248-428-2799 x2997
Ceriasker@beaumonthospitals.com

MINNESOTA-MINNEAPOLIS
Hennepin/Southdale Library
1st Monday: 6:45-9:00 PM
Colleen M. Endrizzi 952-545-0200
rivers3jvk@aol.com

MISSOURI-ST. LOUIS
St. Louis University Cancer Center
9th Friday: 10:00 AM - 12:00 noon
Deborah S. Mann, RN, RDH, RDN, OCN 314-577-8880
mannedt@slu.edu

MONTANA-BOZEMAN
Bozeman Deaconess Hospital
3rd Thursday: 12:00 Noon-1:00 PM
Doug Stiner 406-586-0828
nancydoug@theglobal.net

NEBRASKA-OMAHA
Methodist Cancer Center
Meetings Quarterly
Susan Stensland 402-559-4420
sstensland@nebraskamed.com

NEW JERSEY-MORRISTOWN
Morristown Memorial Hospital
3rd Wednesday: 1:30 PM
Edie Bosch, RN, APN-c, OCN 973-971-4144
Edie.Boschen@atlantichealth.org

NEW JERSEY-PRINCETON, UMC
1st Wednesday: 12:00-1:00 PM
Amy Heffern 609-575-7949
ahheffern@mac.com

NEW JERSEY-SOMERVILLE
Steepleshare Cancer Center
2nd Wednesday: 6:00-7:30 PM
Kelly Harth, MSW, RYT-500
908-343-8247
kharth161@comcast.net

NEW YORK-BUFFALO
Roswell Park Cancer Institute
3rd Tuesday: 4:30-6:00 PM
Amy Sumbrum, SLP 716-845-4947
amy.sumbrum@roswellpark.org
Jim Smaldino 716-845-4472
james.smaldino@roswellpark.org

NEW YORK-ALBANY
ACS Hope Club
3rd Thursday: 7:00-9:00 PM
Kathy Rosbrook 518-758-1333
okroz@aol.com

NEW YORK-BUFFALO
Roswell Park Cancer Institute
3rd Tuesday: 4:30-6:00 PM
Amy Sumbrum, SLP 716-845-4947
amy.sumbrum@roswellpark.org
Jim Smaldino 716-845-4472
james.smaldino@roswellpark.org

NEW YORK-NEW HYDE PARK
Mount Sinai Medical Center
3rd Tuesday: 3:00 PM
Margot Wankoff, LMSW 212-241-7962
margot.wankoff@mountsinai.org

NEW YORK-ROCHESTER
Mount Sinai Medical Center
3rd Tuesday: 3:00 PM
Margot Wankoff, LMSW 212-241-7962
margot.wankoff@mountsinai.org

NEW YORK-NEW HYDE PARK
NORTH SHORE-LIJ Health System
Hearing and Speech Conf Rm.
1st & 3rd Thursday: 2:00 PM
Christine Nolan, LCSW 212-731-5141
christine.nolan@nyumc.org

NEW YORK-ROCHESTER
Strong Memorial Hospital
1st Thursday: 4:30-6:00 PM
Sandra E. Sabatka, LMSW 585-276-4529
Sandra_Sabatka@URMC.Rochester.edu
CHAPTERS OF SPOHNC

NEW YORK- STONY BROOK
Ambulatory Care Pavilion
Wednesday: 6:45-8:15 PM
Dennis Stanopoli 631-682-7103
den.star@hotmail.com

NEW YORK- SYOSSET
NSLIJ-Syosset Hospital
2nd Thursday: 7:30-9:00 PM
Christine Lantier 631-757-7905
clantier@optonline.net
Mary Ann Caputo 516-759-5333
mary.ann.caputo@spohncc.org

NEW YORK- WESTCHESTER
White Plains Hospital Cancer Center
2nd Thursday: 7:00 PM
Mark Tenerzi 914-328-2072
tenerzi@optonline.net

NORTH CAROLINA- ASHVILLE
Call for additional information
Kathleen Godwin 828-692-6174
kgodwin@morrisbb.net

NORTH CAROLINA- CHARLOTTE
Blumenthal Cancer Center
2nd & 4th Thursday: 1:30-5:00 PM
Meg Turner 704-355-7283
meg.turner@carolinacancer.org
Terri Panchaud 704-364-7119
Trapp66@yahoo.com

OHIO- CINCINNATI
Call for date and location
Deborah Heim, MSN, ANPBC, AOCNP
513-584-4794
deborah.heim@uchealth.com
Angie Keith 513-475-7366
Angie.Keith@ucphysicians.com

OHIO- CLEVELAND
Cleveland Clinic at Fairview Hospital
2nd Thursday: 4:00 PM
Gwen Paull, LSW 216-476-7241
gwen.paull@fairviewhospital.org

OHIO- DAYTON
The Chapel Room One Elizabeth Place
Hank Deneiski 937-832-2677
2nd Monday: 6:00-8:00 PM
hdeneiski@minspring.com

OHIO- LIMA
St. Rita’s Regional Cancer Ctr.
Alliance Ctr. Garden Conf Rm
3rd Tuesday of even month: 5:00 PM
Holly Metzger, LMSW 419-996-5606
bjmetzger@health-partners.org
Lisa Gliorioso 419-996-5616
ldgliorioso@health-partners.org

OKLAHOMA- TULSA
Hardy Library Public Library
1st Tuesday: 6:30 PM
Christine B. Griffin, RN 918-261-8858
bergriffin@cvc.net

OREGON- MEDFORD
Providence Medical Center
2nd Friday: 12:00-1:30 PM
Richard Boucher 503-269-8323
richard.boucher@hp.com

OREGON- THE WILLSMERE VALLEY
Samaritan Reg CA Ctr Library
2nd Wednesday: 5:00-6:30 pm
Lisa Nielsen 541-757-9882
HNCSurvivor@comcast.net

PENNSYLVANIA- HARRISBURG
Health South Lab
3rd Tues: 6:30 PM
Joseph F. Brelsford 717-774-8370
jfbrelsford1@mmm.com

PENNSYLVANIA- MONROEVILLE
Inter Community Cancer Center
Last Friday of month: 3:00 - 4:00 PM
Beth Madrishin 412-856-7740
bmadrish@wpahs.org

PENNSYLVANIA- NEW CASTLE
UPMC Jameson Cancer Center
Medical Arts Bldg Suite 104
3rd Thursday: 5:00-7:00 PM
Jeannie Williams, Patient Navigator
Becky Rainville, RN
724-656-5870

PENNSYLVANIA- PHILADELPHIA
Penn Med Perelman Ctr Advanced Med
1 W. Pavilion Pt Fam Conf Rm
1st Saturday: 9:00-11:00 AM
Micki Naimoli 215-662-6193
lautenbach@uphs.upenn.edu

Pennsylvania- York
Apple Hill Medical Center
2nd Wednesday: 5:00 PM
Dianne S. Hollinger, MA, CCC-SLP
Dhollinger@wellsplan.org
DianeMcElwain, RN, OCN, M.Ed
717-741-8100
dmcElwain@wellsplan.org

PENNSYLVANIA- YORK
UPMC CancerCenter
1st Saturday: 4:15-5:30 PM
Jeanne Richelson 423-894-9215
Jeanne1255@aol.com

PENNSYLVANIA- YOKE
Penn State CancerCenter
2nd Monday: 6:00 PM
Elizabeth Wiederholt
wiederholt@hmonc.wisc.edu

TENNESSEE- CHATTANOOGA
Memorial Hospital
1st Monday: 4:15-5:30 PM
Alicia St. Clair 423-903-8211
allicia@health-partners.org

TENNESSEE- NASHVILLE
Gilda’s Club Nashville
4th Monday: 6:00-7:30 PM
Felice Apolinsky, LCSW 615-329-1124
felice@gildasclubnashville.org

TENNESSEE- NASHVILLE
Gilda’s Club Nashville
4th Monday: 6:00-7:30 PM
Felice Apolinsky, LCSW 615-329-1124
felice@gildasclubnashville.org

TEXAS- DALLAS
Baylor Irving-Coppell Medical Center
2nd Saturday: 10:00 AM
Dan Stack 972-373-9199
danstack@ail.com

TEXAS- FORT WORTH
Moncrief Cancer Resources
2nd Wednesday: 5:30-6:30 PM
Marla Hathcoat, LMSW 817-838-4866
marla.hathcoat@moncrief.com

TEXAS- HOUSTON/ TOMBALL
Tomblast Regional Hospital
2nd Tuesday: 12:00 Noon-1:30 PM
Lynda Tustin, RN 281-401-5900
ltustin@tomballhospital.org

TEXAS- MCALEN
Rio Grande Regional Hospital
2nd Tuesday: 6:00 PM
Stephanie Leal, MA,CCC, SLP
SAL1275@aol.com
Cheryl Lopez, MS, CCC, SLP
956-632-4016

TEXAS- PLANO
Regional Medical Center at Plano
2nd Tuesday: 6:00-8:00 PM
Polly Candela, RN, MS
214-820-2608
Polly@candela@baylorhealth.edu
Emily J. Gentry, RN
214-820-2608

VIRGINIA- CHARLOTTESVILLE
Dept. of Forestry Building, Suite 800
Last Thursday of month: 11:30-1:00 PM
Viki Bravo 434-982-4091
vbsbnr@virginia.edu

VIRGINIA- FAIRFAX
Inova Fairfax Hospital Radiation/Oncology
2nd Tuesday: 5:30-7:00 PM
Corinne Cook, LCSW 703-776-2813
Corinne.cook@inova.com

VIRGINIA- NORFOLK
sentara Norfolk General Hospital
3rd Monday: 7:00 PM
Cynthia Gilliam 757-770-4199
beachdolphin@aol.com

WASHINGTON- SEATTLE
Evergreen Hospital Medical Center
Red One Conf Room Green-1 245
2nd Wednesday: 6:00-8:00 PM
Kile Jackson 425-788-6562
kile.jackson@hotmail.com

WASHINGTON- SEATTLE
Swedish Med Ctr. 1 E Conf Rm
3rd Thursday: 6:00-7:30 PM
Susan (Sam) Vetto, BSN, RN, BC
206-341-1720  susan.vetto@vmc.org
Joanne Fenn, MS, CCC-SLP 206-215-1770
joanne.fenn@swedish.org

WISCONSIN- MADISON
Univ of Wisconsin Hospital
ENT Clinic Rm. G3/206
1st Wednesday: 11:30-1:00 PM
Rachael Kammer, MA, CCC, SLP
717-851-2601
vsb4n@virginia.edu
Gordon Putnam, M. Div, MA
Gp4d@virginia.edu

WISCONSIN- MILWAUKEE
Medical College of Wisconsin
Conference Rm. J, Rm. 1010
2nd Wednesday: 4:30-5:30 PM
Tammy Wigginton, MS, CCC/SLP
414-805-5662
twiggint@mcw.edu

P.O. Box 53, Locust Valley, NY 11560-0053
1-800-377-0928
SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER
P. O. BOX 53
LOCUST VALLEY, NY 11560-0053

SPOHNC needs your help!

Please update your contact information, including e-mail address if applicable. We want to keep you up to date with news and important information.

Call our office at 1-800-377-0928 with updated information or email us at info@spohnc.org

THANK YOU