A MULTIDISCIPLINARY TEAM OF PHYSICIANS PIECE TOGETHER A DIAGNOSIS FOR A PATIENT WITH AN UNCOMMON CONDITION

A Medical MYSTERY
One day in spring 2011, Bill Johnson looked in the mirror and noticed that his face was drooping. He found that his eyes couldn’t water, and his right eye wouldn’t close all the way. Concerned, the Arlington resident went to see his primary care doctor, who thought it might be Bell’s palsy, a sudden and usually temporary weakness in the facial muscles. “It should clear up in a few weeks,” he was told.

A month later, the drooping hadn’t improved; in fact, a friend noticed that it was getting worse. Johnson and his wife, Carter Echols, went to the local emergency room. At the end of a long night of scans and tests, a neurologist told them some good news—the images did not reveal an explanation for his symptoms—and some bad news: Johnson had an “atypical” case of Bell’s palsy, one with no explanation. “Everyone said, ‘You’ll just have to live with it,’” Johnson recalls.

‘SOMETHING IN MY HEAD’

For four years, his condition slowly worsened: more facial drooping, along with numbness, tinnitus and hearing loss. His balance was off, too. “Walking up the street, I’d be leaning as if I was being buffeted by the wind, even if there wasn’t any,” he says. A hearing specialist suggested more scans. And that was when, in June 2015, “they found something in my head,” he says. Behind his right ear, “where the balance, hearing and facial nerves meet,” was a benign tumor called a schwannoma, Johnson was told. “The doctor said, ‘That explains it. We can get that out in two seconds.’ But there was just something about it that was too cut and dry. I wasn’t ready to have someone operate on me so quickly.”

Johnson and his wife reached out to acquaintances in the medical profession to find out more about his options. One of his wife’s friends, an anesthesiologist at Suburban Hospital, recommended that if he decided to go ahead with surgery, “Dr. Wade Chien is your person.”

NOT YOUR TYPICAL DOCTOR

Fittingly, for such an atypical case, Wade Chien, M.D., is an atypical surgeon. An associate professor of otolaryngology-head and neck surgery at Johns Hopkins School of Medicine, he spends one day seeing patients in Baltimore, another day seeing patients at his clinic at the Johns Hopkins Health Care and Surgery Center in Bethesda, and the rest of the week as a researcher at the National Institutes of Health, where he is developing gene therapy treatments for patients with hearing loss. “That gives me a different perspective,” Dr. Chien notes. “When I’m taking care of patients, I’m seeing issues that can go back and inform my research. And in my research, I’m constantly looking for ways to impact patient care.”

“Immediately, I could see he was interested in me as a person, rather than being interested only in my tumor, or my case,” Johnson says. “Dr. Chien explained the options and courses of action. He also explained how the Hopkins system is interconnected—I could have the surgery in Baltimore, follow up with him as an outpatient in Bethesda, and get the scans I needed at Suburban. We began to experience the teamwork among Hopkins physicians that has so impressed us throughout this journey. They work together and put their patients first.”

AGGRESSIVE SURPRISE

On Dec. 2, 2015, Dr. Chien and Johns Hopkins neurosurgeon Rafael Tamargo, M.D., operated on Johnson to remove the tumor. “Everything went well, and by day two I was up and walking better than I had in months,” Johnson says. But the next afternoon, Dr. Chien arrived with bad news. “He came up on his day off to report that it wasn’t a benign tumor after all,” Johnson says. It was an aggressive squamous cell carcinoma—the second most common type
of skin cancer. It had wrapped itself around the facial nerve, leading toward the brain.

Radiation therapy was needed to prevent the cancer from recurring elsewhere along the pathway where it had originated in the facial nerve and in the area where it had been taken out. But for someone with a full-time job in Washington, the prospect of moving to Baltimore for treatment was problematic. So, the staff at Johns Hopkins recommended Brandi Page, M.D., assistant professor in radiation oncology and molecular radiation science at Johns Hopkins School of Medicine and a member of the Johns Hopkins Kimmel Cancer Center, who treats patients at Suburban and specializes in the treatment of head and neck and brain tumors. “The great thing about Suburban is that I could get there in 35 minutes every morning,” Johnson says.

“Because of the type of cancer, we knew surgery wasn’t going to be enough,” says Dr. Page. Mr. Johnson and his wife had very thoughtful questions,” she adds. “They really wanted a team approach.”

THE TEAM APPROACH
Dr. Page took the puzzling case to two multidisciplinary tumor
boards, in which Johns Hopkins physicians from many different specialties and locations meet to discuss difficult treatment decisions and to teach medical students and residents.

“We decided that it had started somewhere on his skin on the side of the face, and then a primary skin cancer had traveled to Mr. Johnson’s inner ear and wrapped around one of the branches of his facial nerve headed toward the brain,” Dr. Page explains. She designed a careful radiation plan that would direct several weeks’ worth of radiation at the location of the tumor, plus areas where it could have originated in the base of the skull. “He did well, and we all followed his case,” Dr. Page adds. “That’s what we do in a multidisciplinary setting: we all can have eyes on the patient, and we knew because of his unique presentation that we all wanted to keep watch because the risk of recurrent cancer is high.”

For more than a year, everything went well. Johnson would come to Johns Hopkins Medical Imaging in Bethesda and Suburban for follow-up scans, and he always checked in with Dr. Page. “He said that we are his ‘home base,’ and that’s great to hear,” Dr. Page says. “Although I am faculty at Johns Hopkins, my patients here in the Washington, D.C., region are like my own neighbors or family members.”

INNOVATIVE IMMUNOTHERAPY

In June 2017, Johnson started investigating pains in his neck and significant loss of muscle mass in his right shoulder. When this happened, Dr. Page ordered new scans and found something chilling. “The cancer had jumped into his spinal canal and spread into his spine,” Dr. Page says. The condition, known as leptomeningeal carcinomatosis, has a grim prognosis. The location meant surgery was out of the question, and radiation wasn’t an option, either. But Dr. Page knew who to call: an expert in a new type of cancer care, immunotherapy, who splits his time between Johns Hopkins in Baltimore and the Johns Hopkins Kimmel Cancer Center at Sibley Memorial Hospital. “There are very exciting developments ongoing in immunotherapy for cancer treatment,” says Dr. Page. “Right now, we’re taking advantage of immunotherapy in many different cancer types.”

“He came in with a really tough problem to treat,” says Evan J. Lipson, M.D., medical oncologist at the Johns Hopkins Kimmel Cancer Center at Sibley and associate professor of oncology at Johns Hopkins School of Medicine. “However, in the past several years, Johns Hopkins has led multiple clinical trials demonstrating that immune-based
RAISING MONEY ONE MILE AT A TIME

In early 2011, North Bethesda resident Victoria Chipa went for a routine annual mammogram and received a diagnosis of breast cancer. After surgery and radiation treatments at Suburban Hospital, she made a full recovery. Grateful for the exceptional care she received during that time, she embarked on a very special and personal fundraising walk.

Over the course of a weekend in May 2018, Victoria walked 53 miles, alone, from her home to Downtown Washington, D.C., and back again. Thanks to the generosity of others, she raised $3,000 for the Suburban Hospital Breast Cancer Patient Navigator program.

“The care and support I received during a difficult time in my life made a huge impact on me, and it was important to me to give back to those who were instrumental in my recovery,” she says. “I plan to walk again in 2019 … and raise even more money!”

Therapies can successfully treat patients with various types of cancer.” Armed with this experience, Dr. Lipson recommended treatment on a trial led by his colleague Jarushka Naidoo, M.B.B.Ch., assistant professor of oncology at the Sidney Kimmel Comprehensive Cancer Center in Baltimore. The trial was investigating the safety and efficacy of pembrolizumab, an immunotherapy that targets a molecule called PD-1, which regulates activation of the immune system.

‘TRULY PERSONAL CARE’

Once Dr. Lipson and his team began treating Johnson, they arranged for as many study visits as possible to take place at Sibley. “Not infrequently, I’ll see a patient in Washington and enroll them in a clinical trial that we have open in Baltimore,” says Dr. Lipson. “We’re working hard to make as many of our Baltimore-based clinical trials as possible available at Sibley and Suburban.”

“They said, ‘You probably don’t have to quit work to do this,’” Johnson says. “The staff in my office has been incredibly supportive. Drs. Lipson and Naidoo arranged my study treatment schedule to see me every third Tuesday in Baltimore, and I get my scans in Bethesda. All the systems work together, so no matter which facility I go to, everyone is on the same page, and has access to the same information. I felt this incredible support throughout the whole experience. It’s truly personal care.”

EXPERT CARE, CLOSE TO HOME

The case is a perfect example of the synergies possible with the collaboration among the Sidney Kimmel Comprehensive Cancer Center team in Baltimore, as well as the Johns Hopkins Kimmel Cancer Center team in the Washington, D.C., region, Dr. Page adds. “I can pick up the phone and call Dr. Lipson or Dr. Chien, and we’ll respond back and forth quickly,” she says. “We are bringing all these specialists together, using the expertise at each of the sites, and we can systematically problem solve between all of them. If you want multidisciplinary, collaborative care, you need to go to a place that takes this approach. We are pooling our resources to select the right mix of services for each individual patient.”

Today, Johnson has had a remarkable response to treatment. The pain is gone, muscle mass has improved, and tumors are not visible on scans. “It’s amazing to have access to world-renowned health care so close to where I live,” Johnson says. “We feel very blessed to be here. The sense of care and compassion and competence by the team of doctors in the Hopkins system has been amazing.”

For more information about the Johns Hopkins Kimmel Cancer Center in our region, please visit HopkinsCancerDC.org to watch a video with Dr. Brandi Page.