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When Kevin had stroke at 13, technology gave him a chance

By Brian Alexander
Seattle Times staff reporter

Kevin Rhee sat cross-legged on the field, pulling up grass with his right hand.

Around him, it was Campus Day at Alderwood Middle School. Other kids were playing soccer and basketball, and scaling an inflatable climbing wall. But Kevin just pulled up grass.

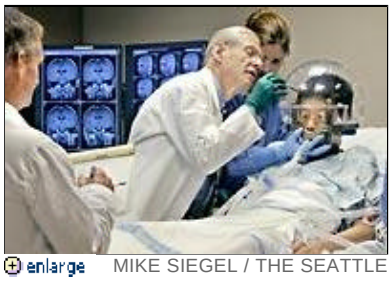
Once upon a time, Kevin, who came to Lynnwood two years ago from South Korea and turned 14 Monday, would have played alongside the other kids, but on that particular day he just worked on creating a brown spot amid the field of green.

Kevin was frustrated.

Two months earlier, he had hoped to become an astronomer.

Or maybe a doctor. Or a cartoonist.

PREV | 1 of 6 | NEXT



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Neurosurgeon Robert Goodkin, center, takes measurements with the help of nurse manager Jodie Lee as they prepare Kevin Rhee for gamma-knife radiation to target an abnormal mass in his brain. Dr. Jay Douglas, left, a radiation oncologist at Harborview Medical Center, records the data.

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A photo gallery of Kevin's story

But the day before, he was at Harborview Medical Center, a metal frame attached to his skull, while a neurosurgeon and a radiation oncologist made plans to obliterate an abnormal mass in his brain that was no bigger than Lincoln's head on a penny.

They would use a computer-controlled machine called a gamma knife, which they hoped would destroy the maze of problematic arteries and veins called an arteriovenous malformation (AVM).

A cerebral AVM afflicts about 1 in 1,000 people in this country, according to the National Institutes of Health. Often present from birth, doctors say, the mass can hide until one day it ruptures, causing a stroke.

"It's like living with a time bomb," said Dr. Jay Douglas, a radiation oncologist at Harborview.

Kevin's bomb went off March 7.

Began with a nosebleed

It started like any weekday.

Kevin woke up and took the bus to school. But then he had a nosebleed during first period. Kevin was sent to the office, and the bleeding stopped. He felt OK.

Third period was P.E.

To his teachers, Kevin is known as a good, quiet, respectful student, with a 4.0 grade-point average.

He had been through a lot the past two years, said Ae Ja Kim, his mom. Kevin mostly kept to himself when the family suddenly moved to Lynnwood from South Korea to avoid a custody battle with her former husband. They rented an apartment in which Kevin, his brother and his mom share a bedroom.

Kevin wasn't one to complain.

So when he approached his P.E. teacher and asked to go to the office because he wasn't feeling well, the teacher said OK.

He had been running — he loved running; he was on the cross-country team — when "all of a sudden I got a headache," he said. He felt dizzy, he had trouble moving his left arm and leg. He was scared.

AVM facts

What it is: Arteriovenous malformation (AVM) is a tangle of vessels and arteries that are directly connected, avoiding capillaries. In a normal circulatory connection, capillaries serve to regulate pressure in the area as well as exchange nutrients for waste to the surrounding tissue.

Cause: Doctors don't know what causes the tangle of vessels, which afflicts about 300,000 Americans, according to the National Institutes of Health (NIH).

Symptoms: About 12 percent of those who have AVMs experience regular symptoms that can include headaches, seizures or vision problems. Those afflicted may lack symptoms for years or have headaches that are blamed on other things. AVMs tend to be discovered incidentally, often through treatment for another ailment, according to the NIH. A lucky few may live a full life without knowing they have an AVM.

Risk: There's a 2 to 4 percent chance per year that a cerebral AVM will rupture in what doctors call a "bleed," which is essentially a hemorrhagic stroke. A bleed may not cause noticeable damage, depending on the location of the AVM and severity of the bleed. After a bleed, the risk of future bleeds can increase as much as 10 percent per year. Over a normal life span, chances are almost 100 percent that the mass will cause a stroke.

His AVM had burst. Slowly, a 2-centimeter spot of blood was forming deep inside the right hemisphere of his brain. He was suffering a stroke.

He remembers walking to the office as his left arm, which hung limp from his side, swung loosely and hit against door frames. His left leg dragged as he stumbled down the hallway.

In the office, his condition worsened. The principal, Suzie Baier, found him slowly slipping from consciousness.

The school office called Kim on her cellphone and left messages, but she was in class as a student at Bellevue Community College and had turned her phone off.

The voice-mails left on her phone got progressively worse.

"I could not listen to my cellphone because it was too scary," Kim said. "My heart was pounding."

Kevin was being taken to Children's Hospital & Regional Medical Center.

He remembers falling over in the nurse's office and the paramedics arriving. He remembers fingers being waved in front of his face and people asking him questions. He remembers the oxygen mask.

His eyes closed.

The procedure

Three months after his AVM burst, Kevin was being prepared for the gamma-knife procedure at Harborview. He was quiet and looked calm, giving doctors monosyllabic answers as they described the procedures and asked if he understood the risks. When he was hooked up to the electrocardiograph, though, everyone could hear the staccato of his anxiety.

Kevin and his mom had stayed at Children's Hospital for 45 days after the incident, and though he had recovered some, he had limited use of the left side of his body.

His treatment was going to be on a gamma-knife machine, model 4C, that the hospital had purchased a month earlier. This model, doctors said, was among the most advanced in the nation, and Harborview was the first on the West Coast to have it. It allowed them to import several brain images and make a treatment plan using a video-gamelike computer program.

The machine focuses 201 beams of radiation at a single spot in the brain in hopes of obliterating the tumor, lesion, AVM or other abnormal growth.

It's like being in a forest at night with 201 friends, each with a flashlight, Douglas explained. One flashlight by itself isn't too bright, but when all those friends stand in a circle and shine their lights at a single spot in the center, the effect is much more intense.

It's the same with the gamma knife, he said. Except instead of flashlights, there are 201 sources of radiation, and they're all aimed at the AVM. The system allows doctors to target abnormalities deep inside the brain while limiting effects on healthy brain tissue.

On June 20, at about 7 a.m., Kevin was put under general anesthesia as a metal frame was screwed into his skull. The "stereotactic head frame" would allow doctors to line up an MRI with a CT scan and a cerebral angiogram, which shows the location of blood vessels in the brain. Those would be combined into one detailed digital image on which they'd prepare Kevin's AVM treatment plan.

For this treatment, a scalpel had been replaced by a cursor on a computer screen, and a doctor's precise hands had been replaced by a computer program.

Images taken in other parts of the hospital, where Kevin's brain had been scanned and rescanned, were sent to a small room near the Gamma Knife Center. Inside, doctors outlined Kevin's problem area.

The outline would be translated into the treatment that would be performed

by the computer using the gamma knife. Before computing power allowed gamma-knife operations to be automated, it took eight hours of hand calculations to create a plan, Douglas said.

"In many ways, it's like a video game, where our object is to match our dose to the area we've outlined," he said.

Prior to the gamma knife, which was developed by a Swedish physician and first used in 1968, a patient with an AVM deep within his brain like Kevin wouldn't have had any reasonable surgical option, Douglas said.

"If you did surgery, you would do more damage than good," he said. "He'd live with a chance to have another bleed."

When Kevin awakened from the anesthesia, his head frame was attached to the gamma knife in a small, sterile-looking room. During the treatment, he would be alone but could listen to music to help time pass. He chose a CD a friend had made for him, titled "Kevin Rhee's Mix" — Christian songs in both Korean and English.

As the heavy door closed and a light above it lit up — "Gamma Knife in Use" — Kevin was alone with the machine that would perform the operation.

Back home

One of Kevin's favorite video games is "Halo 2," but he still doesn't have full use of his left hand, which is usually used to control a thumbstick.

He has, however, adapted: He uses his chin.

Kevin spends much of his time now drawing, reading, playing video games, doing his rehab exercises and watching TV. He takes short walks around the apartment to strengthen his leg. His brother Cody, 11, helps tie his shoes.

"He looks a little bit sad sometimes because he cannot walk, and he cannot run," said his mom. "My Kevin" doesn't talk much about his frustration, she said, but when he sees other kids playing, running or doing something he can't, "his eyes tell something to me."

The AVM and the stroke have "hurt his dream," she said.

Doctors expect Kevin will recover most of the motor function he lost from the stroke, though they stop short of saying he'll make a full recovery.

Research published by physicians from the Mayo Clinic found that about three-fourths of patients who had one or more gamma-knife operations for an AVM had "excellent" or "good" long-term results.

Douglas said Kevin has a 95 percent chance his AVM will be cured with only one treatment. He'll have to return to the hospital every few months for brain scans to check on the mass.

It can take between six months and two years for an AVM to completely recede, and in that time Kevin lives with the risk of another bleed.

"It's like doing surgery, although we don't see the immediate results of doing

surgery," said Dr. Robert Goodkin, a neurological surgeon at Harborview. But, he added, Kevin's AVM was small enough that there's likely not going to be anything left of it in six months.

In the meantime, Kevin has two hours of therapy two days a week. He's serious about his exercises. He said he can notice himself improving.

Kevin's mom is taking time off from her classes and only recently returned to work.

The family's living expenses have been partly paid for by a walkathon put on by Kevin's middle school. While he was at Children's Hospital for 45 days, Kim never left Kevin's side. The students, teachers and staff, seeing the family's situation, walked around the school parking lot and raised about $12,000 for the family.

Kim is grateful for the support she has received from a community she has been a part of for only a little more than two years.

She hopes to volunteer at Children's Hospital someday and find other ways to repay the hundreds of thousands of dollars in medical bills that increase with every therapy visit.

Despite all that has happened, the bitterness that prompted the move from South Korea, the financial struggles as Kim takes classes and works part time, and now Kevin's AVM, the family has maintained faith. They believe, though life is often trying and difficult, that all will be OK.

"Frankly speaking, I feel very scared. Can I survive here? If I do my best on a daily basis, my God will take care of me," Kim said, trying to look on the bright side. "Kevin will be a better person because of this."

Brian Alexander: 206-464-2204 or balexander@seattletimes.com

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