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WOMAN WHO CAN HEAR HEARTBEAT, FOOD DIGEST, EVEN HER EYES MOVE, UNDERGOES LIFE-CHANGING SURGERY AT UCLA

Condition caused by tiny holes in bone encasing inner ear; medical team uses state-of-the-art technology to plug them

Los Angeles, CA. - Rachel Pyne says at times the sounds in her ears were deafening and inescapable. Her footsteps rumbled through her head like thunder, she could hear her heartbeat, her food digesting, and even the shifting of her eyes.

"It was crazy. I could hear my eyes swoosh around as I moved them back and forth," said Pyne, "Like moving your hand in water."

Along with the noises, Pyne also began to lose her balance and suffer debilitating dizziness and nausea. It wasn't long until her symptoms affected every aspect of her life.

"I couldn't even fall asleep. I would lie there and wish that my head would stop spinning," she said. "It was just chaos in my ears."

At the age of 27, Pyne, a photographer from Merrillville, IN, had developed a rare condition known as superior semicircular canal dehiscence, or SSCD.

"Basically, it's a hole that develops between the inner ear and the brain," explained <u>Dr. Quinton</u> <u>Gopen</u>, an ear surgeon at <u>Ronald Reagan UCLA Medical Center</u>. "That region of the inner ear has sealed compartments with little fluid chambers, and occasionally a hole will develop in the bone and allow for these problems to arise."

Because SSCD is such a rare condition, affecting an estimated one person per half million, patients often see several doctors before receiving a correct diagnosis, if ever. Pyne was examined by at least nine doctors and specialists all over the country, most of whom attributed her symptoms to migraines.

"One doctor told me I was just going to have to live with it," Pyne said. "That was devastating."

According to Gopen, this type of misdiagnosis is not uncommon. "A lot of these patients are seeking psychiatric help because they're just mentally worn out," he said. "They can't escape the condition and

it really kind of grinds them down."

Pyne had almost given up until she came across an online support group launched by a former patient of Gopen and his colleague, <u>Dr. Isaac Yang</u>, and learned about their approach to similar cases at UCLA.

"We went there and saw Dr. Gopen, and within 15 minutes he diagnosed me and said, 'Absolutely we can do surgery.' I was crying because I had been through so much," Pyne said.

"Patients are relieved to learn that this situation has become routine to us," said Yang, a UCLA neurosurgeon who partners with Gopen on each SSCD procedure. "Because we see a lot of these cases, we not only believe them when they say they can hear their eyeballs or neck muscles move, but we can help them."

After five years of operating on SSCD patients together, Gopen and Yang have developed a minimally invasive surgical technique that patches the hole in the inner ear, restoring normal balance and hearing.

"Traditionally, you'd need to have a big middle fossa craniotomy," said Yang. "That's a type of surgery that requires a sizeable hole in your skull, which leaves a larger scar and requires a much longer recovery time.

"What we're doing now is performing the entire operation in a hole the size of a dime. That allows these patients to get back to work and get back to their lives much sooner," Yang said.

Before the operation begins, the surgeons use state-of-the-art technology to map the brain and determine precisely where to enter the skull.

"Our neuro-navigation system is like using GPS for the brain," said Yang. "It's like a heat-seeking missile that allows us to target that itty, bitty hole between the inner ear and the brain."

"These holes are only a millimeter or two wide," said Gopen. "That's about the size of the hole in the tip of an ink pen, so we really need to be precise and know exactly where we're going."

Working in tandem, Yang, the neurosurgeon, opens the skull and lifts the brain, then Gopen, the ear surgeon, pinpoints the tiny hole in the inner ear bone and plugs it with an artificial filler called bone wax. The entire procedure lasts roughly 90 minutes, and results are usually instantaneous.

"As soon as I woke up from surgery I was like, 'Oh, my gosh. It's gone!'," said Payne. "Looking back, I'm actually happy that so many doctors turned me away and told me they couldn't help, because Dr. Gopen and Dr. Yang did. I'm just so thankful."

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