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BUSINESS › JOBS

Breast pumping rooms for working mothers aim to boost retention, recruitment

Lactation suites are coming to Dallas this fall, thanks to Work & Mother.

By Irene Wright
7:00 AM on Aug 18, 2022 CDT

Jules Lairson, chief operating officer and director of strategy and business development for Work & Mother, posed as construction continued for the new Work & Mother's breastfeeding amenity location for the Lincoln Centre on Aug. 17, 2022, in Dallas. (Juan Figueroa / Staff Photographer)

LISTEN

More than 75% of new mothers try to return to work after having a baby. Less than half make it through the first year.

One of the major obstacles women face when returning to work after having a child is finding a safe and comfortable place to pump breast milk.

To tackle the issue, lactation suites are coming to Dallas this fall, thanks to Work & Mother. The company designs and builds shared corporate lactation suites where working mothers can go and pump breast milk while at work in a safe and comfortable way. By creating a shared space in an office building, it reduces the costs for individual businesses and landlords.

Designated pumping areas are required by law, but many businesses don't have them, or if they do, they're in an

area that doubles as a conference room, a private office or even a supply closet.

“We’re having some landlords call because they say ‘Okay, we just did all these really cool amenities. We’ve got foosball and tenant lounges, but we have moms pumping [breast milk] in closets,’” said Abbey Donnell, co-founder of Work & Mother. “They’re starting to see there’s another half of the equation as far as who is working in their buildings.”

Described as “spa-like but professional,” the suites look like a small locker room space or spa changing area, and they provide private rooms for women to pump.

Work & Mother Lactation Suite

4 IMAGES

Each room is stocked with a hospital-grade pump, milk storage bags, lanolin breast pads and cleaning solutions, and the mother brings her own attachment set, the part of a breastfeeding kit that touches the body and the breast milk.

“Our moms literally come to work with nothing extra and they leave with just their milk,” Donnell said. “It’s very freeing to allow them to focus on work when they’re at work and their family when they’re at home.”

Donnell said employers around the country are struggling to find new hires, and working moms are a large demographic for potential talent. The lactation suites can be an important amenity for businesses as employees

return to the office.

Abbey Donnell is the CEO and co-founder of Work & Mother, a group that creates shared lactation suites in corporate spaces for working mothers. (ttweak)

“It’s an extremely tough time to be a mom, especially a working mom, and if employers don’t adapt to supporting the workforce in that way, they’re not going to be able to hire,” Donnell said. Businesses should “set an example of what the standards and support and humanity and decency of a working mom situation should look like.”

Suzanne Brown used conversations she had with women in her life, as well as her own pumping experience, to start Mompowerment, a workplace strategy group that helps working moms get back into the workforce and advocate for their needs. Brown, an author, public speaker and consultant, has interviewed hundreds of moms about their experiences.

“What I normally hear about is the nightmare side of trying to figure out how to pump where you’re like in a women’s restroom trying to manage pump equipment along with nothing falling in the toilet and not having anything touch the floor,” she said.

Brown admitted she was lucky when she went back to work. Her company had two dedicated pumping rooms, one equipped with a hospital-grade pump. She said, however, this was not the norm. Though having a pumping location is required by law, the language is vague, and employers are only required to have a “dedicated space” for mothers.

Brown said it’s “a relative term as far as a dedicated space. That could literally be a supply closet where anybody can open the door.”

Suzanne Brown, founder of Mompowerment, helps women get back into the workforce through her books, public speaking and consulting. She, too, is a working mom. (Robert J. Paulsen)

Brown regularly works with women to help them advocate for themselves in the workplace and share with their employers what they need in order to be a productive employee, whether that is breast-pumping amenities, flexibility in their schedules or moving to a part-time position.

What is not an option, she said, is for breastfeeding women to be told they should just work from home.

“There’s no question that there is a difference between being seen in the office, having those conversations, having those what we call ‘random touch points’ with decision makers and senior leadership where you’re walking down the hallway and they recognize you from a meeting,” Brown said. “You miss this when you work from home.”

Brown said employers should see lactation suites or breastfeeding amenities as a way to recruit and retain mothers. “The pandemic really kind of pulled back the curtain on the realities of working motherhood, and that’s one of the benefits of what happened,” she said. During the worst of the pandemic, 1.4 million mothers left the workforce.

Facilities like Work & Mother offer a space where mothers can work while they pump, and pumping can be more productive when a mother is more calm.

Work & Mother’s first Dallas location will open at Lincoln Centre in October as part of a $43 million overhaul of the complex, according to Jack Nye, director of operations for the center. He says management saw a lactation suite as a necessary amenity for tenants, just like a gym or cafe.

Lactation pods like Mamava can provide the same appeal of a lactation suite but with more flexibility. The pods can be moved around a space once installed, and they’re appealing for smaller businesses that may not be able to construct a larger project.

Mamava has 11 pods in Dallas, two in the Kay Bailey Hutchison Convention Center and the rest in private businesses. The company began launching pods in Dallas in 2017.

“Mamava lactation pods are designed as a private and comfortable space for a parent to breastfeed or pump wherever they go. Sometimes folks are leaving their baby to go to work; other times, they’re navigating public spaces, with or without their child,” said Mamava co-founder and chief brand officer Sascha Mayer. “In every case, breastfeeding and pumping parents need the option of a quiet space equipped with everything a parent needs to nurse or pump.”

Mamava has two pods in the Kay Bailey Hutchison Convention Center in Dallas. (Mamava)

The pods are a less expensive alternative to the lactation suites and start at $10,000 per pod. The pods, once delivered, can be set up in a matter of hours. They don't have equipment or milk storage capabilities, but work well for women on the go.

Mamava and Work & Mother are able to provide a network of pumping locations across Dallas-Fort Worth, and both companies have associated apps that moms can use to find somewhere safe and clean to pump.

Mayer agreed that pumping locations should be seen as a necessity for employers.

"Lactation support needs to be recognized as an important health benefit. Lactation support in the workplace benefits both employees and businesses. Working parents who have access to pumping spaces are known to have less days missed at work, higher productivity levels and are more loyal employees," she said.

Mayer said Mamava has gotten more interest from companies since the start of the pandemic, particularly from businesses with front-line workers.

She said that after working from home for two years, "many parents have realized that they have a choice when it comes to creating work-life circumstances that work for them. Businesses understand that it's more important than ever to create inclusive work environments — which means everything from providing schedule flexibility to ensuring that there's a comfortable, suitable place to pump breast milk when they are spending time away from their babies."

Irene Wright, Staff Reporter. Irene Wright covers health, environment, and business for Dallas Morning News. She is a second year master's student in health and medical journalism at the University of Georgia. Irene received a B.A in Ecology from the University of Georgia in May 2021.

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BUSINESS › HEALTH CARE

ReCode Therapeutics attracts $120 million in new investment for its drug delivery tech

The 7-year-old company uses technology developed by co-founder Daniel J. Seigwart of UT Southwestern's Simmons Comprehensive Cancer Center.

By Irene Wright
2:46 PM on Jun 29, 2022 CDT — Updated at 3:52 PM on Jun 29, 2022 CDT

ReCode Therapeutics' experimental drugs could be used to treat cystic fibrosis and primary ciliary dyskinesia, and will branch out to more illnesses with the new funding. (Getty Images/iStockphoto / Getty Images/iStockphoto)

Dallas-based ReCode Therapeutics has raised an additional $120 million from investors to expand its genetic platform that can deliver drugs to selective organs in the human body.

The new money builds on an earlier $80 million funding round for the 7-year-old company using technology developed by co-founder Daniel J. Siegwart of UT Southwestern's Simmons Comprehensive Cancer Center.

New investors include Leaps by Bayer, the investment unit of Bayer AG, Matrix Capital Management affiliate AyurMaya and Amgen Ventures. Alan Colowick, managing director of Matrix, and Rakhshita Dhar, senior

director of venture investments health at Leaps by Bayer, will join ReCode's board of directors in connection with the financing.

Previous backers included Pfizer Ventures and EcoR1 Capital, a San Francisco-based biotech investment firm.

ReCode CEO Shahnaaz Suliman also said there was so much interest in the company's earlier capital raise that it extended the investment round.

ReCode CEO Shahnaaz Suliman (Jennifer Leahy)

"We are on the cusp of a bright future in genetic medicine," Suliman said. "The key to unlocking that future is delivery."

The funding will help ReCode continue research and development of its selective organ-targeting lipid nanoparticle delivery platform.

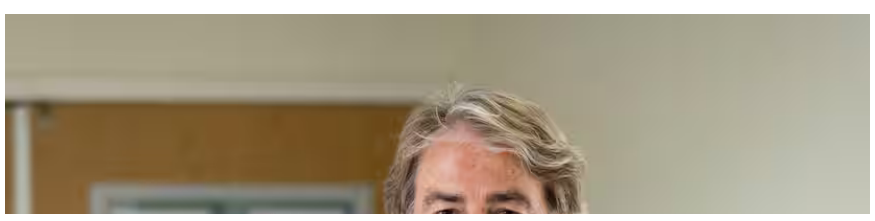
Siegwart "really had the scientific vision to break away from conventional thinking and had the insight to re-engineer the traditional [lipid nanoparticle] platform," Suliman said.

The technology, described by *Nature* as one of "Seven Technologies to Watch in 2022," acts as a drug delivery system, like a suitcase that carries genetic cargo to targeted organs in the body to treat disease.

Lipid delivery systems have been used in other treatments like the mRNA COVID-19 vaccines. But, unlike the COVID vaccines, organ-targeting treatments are engineered with an extra lipid that helps the body to sort where the genetic cargo should go, directing the nanoparticles to specific organs such as the lungs or spleen and bypassing the liver.

"With all the traditional [lipid nanoparticles] in the world, if you put them in the blood they go primarily to the liver," said ReCode chief scientific officer David J. Lockhart. With ReCode's technology, "we can deliver them to the liver if we choose, but we can also de-target the liver for delivery elsewhere in the body. That's really the most unique characteristics."

Previous genetic medicines have struggled to target organs other than the liver because they were delivered through the blood, but Siegwart's technology is capable of targeting specific organs and cell types to maximize the efficacy of genetic medicines and limit potential side effects of long-term drug exposure on liver function.



Siegwart "said let's take what's good about the four component [lipid nanoparticles] and add a fifth lipid that can potentially confer all sorts of important

ReCode President and Chief Scientific Officer David J. Lockhart. (Jennifer Leahy)

properties like increased potency, increased ability to package a large variety of genetic medicine payloads, and then most uniquely, have the ability to tune the bio-distribution properties to not just deliver to the liver," Lockhart said.

ReCode plans to branch out to oncology and central nervous system treatments, as well as alternative forms of drug administration like a nebulizer, or inhaler, for lung diseases, or injection into spinal fluid to directly target the brain.

"The use of proceeds from this financing will be used to expand and diversify the platform to different tissues and organs, but also with different types of genetic cargoes," Suliman said. "The way to think about this is beyond vaccines and beyond the liver, and then with diverse cargoes and diverse modes of administration."

Suliman leads a team of 70 at ReCode, with plans to expand the workforce to 100 in the next six to 12 months.

She was named one of the 2017 Fiercest Women in Life Science by Fierce Pharma and one of the Most Influential Women in Business in 2021 by the National Diversity Council's Power 50. She has more than 25 years of experience growing biopharmaceutical companies, including delivering a $1 billion profit sharing partnership with Janssen while at Theravance Biopharma as senior vice president.

Lockhart previously served as CEO and president of ReCode predecessor TranscriptTx, and served as the chief scientific officer of Amicus Therapeutics from 2006 to 2013. As a biotech executive, he has worked in drug discovery, drug development and technology development for more than 25 years.

ReCode is an inaugural tenant of Dallas' Pegasus Park. The biopharmaceutical development park just saw its first company graduate when cancer therapy startup Aakha Biologics announced a new, permanent headquarters in Frisco.

Related: **Fort Worth biopharma Nacuity lands $16.5 million in eye disease research funding**

Irene Wright, Staff Reporter. Irene Wright covers health, environment, and business for Dallas Morning News. She is a second year master's student in health and medical journalism at the University of Georgia. Irene received a B.A in Ecology from the University of Georgia in May 2021.

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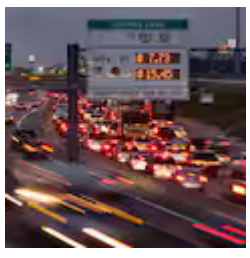

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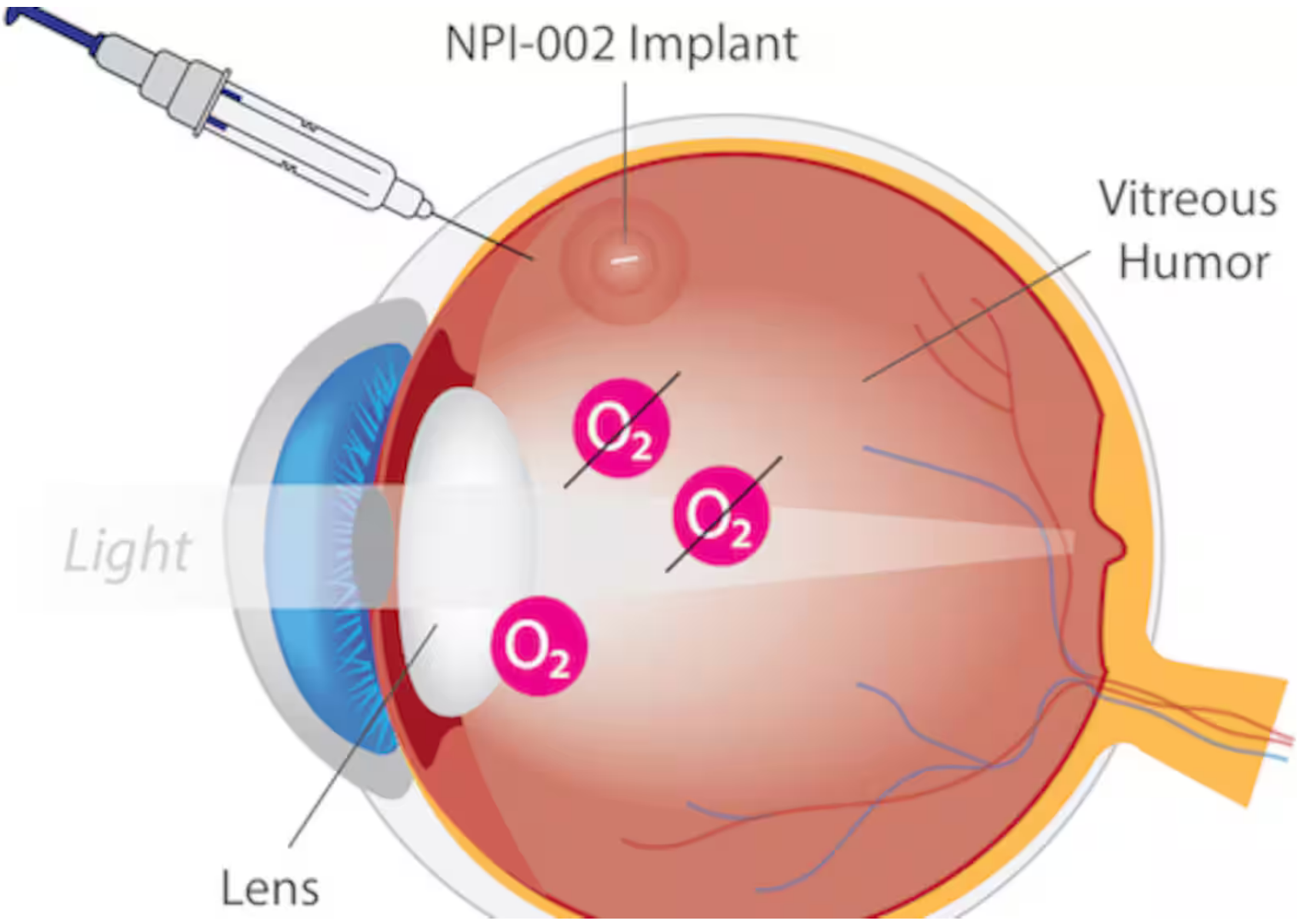
BUSINESS › HEALTH CARE

Fort Worth biopharma Nacuity lands $16.5 million in eye disease research funding

The funding round was led by Foundation Fighting Blindness and was a significant boost from its initial $2 million raise.

By Irene Wright
6:42 AM on Jun 15, 2022 CDT



The treatment for cataracts, a pharmaceutical implant, is inserted into the vitreous of the eye using a precision delivery system following a vitrectomy, eye surgery that removes the vitreous to reach the back of the eye.

Fort Worth biopharmaceutical company Nacuity Pharmaceuticals Inc. will put $16.5 million in new capital into furthering its research of treatments for degenerative eye diseases.

Nacuity is in the clinical stages of developing treatments for retinitis pigmentosa, a group of genetic eye diseases, and other eye diseases caused by oxidative stress. This stress can be created by an imbalance of antioxidants in the eye, making it difficult to repair damaged cells and leading to vision loss.

Nacuity's technology is based on the studies of Dr. Peter Campochiaro at the Wilmer Eye Institute at Johns

Hopkins Medicine on oxidative stress in the retina, the portion of the eye that's sensitive to light. Eye diseases linked to oxidative stress include retinitis pigmentosa, cataracts, age-related macular degeneration, diabetic retinopathy, glaucoma, presbyopia, retinal detachment and vitreous degeneration.

The funding round was led by Foundation Fighting Blindness. It represented a significant boost from the company's initial $2 million raise in 2017.

Nacuity chairman, CEO and co-founder Halden Conner and his team "are great stewards of our dollars. They are smart, transparent, efficient, and with great integrity," said Rusty Kelley, senior vice president of investments for Foundation Fighting Blindness and its venture arm, the RD Fund. "We believe in the science, and we believe in the management team to develop the technology."

Halden Conner, chairman, CEO and co-founder of Nacuity Pharmaceuticals Inc.

Conner said the funding will cover the company's "proof of concept," with results expected in the second quarter of 2023 and continuing to 2025.

"The thing for any small business is to have enough runway to reach your proof of concept," said Conner, who previously co-founded proton therapy technology company ProTom and served on the board of Alcon Laboratories.

Nacuity will use the $16.5 million for two phase I/II clinical trials, one for retinitis pigmentosa patients with Usher Syndrome, and another in patients who have had a vitrectomy, a type of eye surgery that removes the vitreous, or fluid sac of the eye, to reach the retina in the back. The development and progression of cataracts and vision loss are common side effects of vitreous surgery.

Usher Syndrome is treated with a tablet for easy delivery into the body, and while effective in animal models, it is not long-lasting. The treatment used for cataract prevention is an implant into the vitreous that can last much longer, four to six months, but requires surgical implantation. The implantation would occur during a vitrectomy when the natural eye fluid is replaced with a synthetic material.

Gene therapy research on Usher Syndrome "will still take 10 to 20 years to get to the root causes, so we can save a lot of sight in the meantime," Conner said. "We believe that our treatment would be a companion treatment even with gene therapy."

Retinitis pigmentosa affects 1.5 million people worldwide and cataracts affect 65.2 million people, with 80%

resulting in significant loss of sight, according to the World Health Organization.

“Research in the field here can get us some insight into the detailed mechanisms in which cataracts are formed and can be applied to the broader research into cataract treatment and formation,” said Hossein Ameri, an ophthalmologist with the University of Southern California Roski Eye Institute and a member of the American Society of Retina Specialists. He is not involved in Nacuity’s trials.

Conner said the treatments, if successful, could be applied to other oxidative stress eye diseases and cataract conditions.

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NATIONAL

Breast implants kept man alive when he urgently needed new lungs. Doctors explain how

BY **IRENE WRIGHT**
NOVEMBER 09, 2023 4:24 PM

A 34-year-old man from Missouri had a serious lung infection following a flu virus, forcing doctors to remove his lungs. Then surgeons used breast implants to keep his heart in place. *Northwestern Medicine*

David Bauer started smoking cigarettes when he was 21 years old.

The 34-year-old, who goes by Davey, smoked about a pack of cigarettes a day while maintaining an otherwise healthy, active lifestyle of snowboarding, skateboarding, gaming, golfing and working in landscaping in his home city of De Soto, Missouri, just outside St. Louis.

He switched to vaping in 2014 because “vaping felt better and I thought it was the healthier alternative, but in all honesty, I found it more addicting than cigarettes,” he told doctors at Northwestern Medicine in a Nov. 8 news release.

Bauer maintained a relatively active lifestyle, but he also smoked a pack of cigarettes a day before switching to a vape pen in 2014, doctors said. *Northwestern Medicine*

Then, in April of this year, Bauer caught the flu.

For someone with healthy lungs, an influenza A infection is usually not life-threatening.

But for someone who had been smoking, and then vaping, for 13 years, it quickly became serious, the doctors said.

Bauer had shortness of breath, which soon turned into a massive lung infection, one that was resistant to antibiotics, according to the release.

He was admitted to a hospital in St. Louis and placed on an ECMO machine, a device that acts as his heart and lungs.

“Davey’s lungs were so heavily infected that they started to liquify. If you looked at his X-ray, there was nothing left — the lungs were completely filled with puss,” pulmonologist and medical director of the Northwestern Medicine Canning Thoracic Institute Lung Transplant Program, Rade Tomic, said in the news release.

Bauer’s medical team in St. Louis reached out to Northwestern, in Chicago, and the doctors quickly determined Bauer wouldn’t survive long enough for a lung transplant with the infected lungs still inside his body.

“This was uncharted territory for us, but our team knew if we couldn’t help Davey, no one else could,” Tomic said.

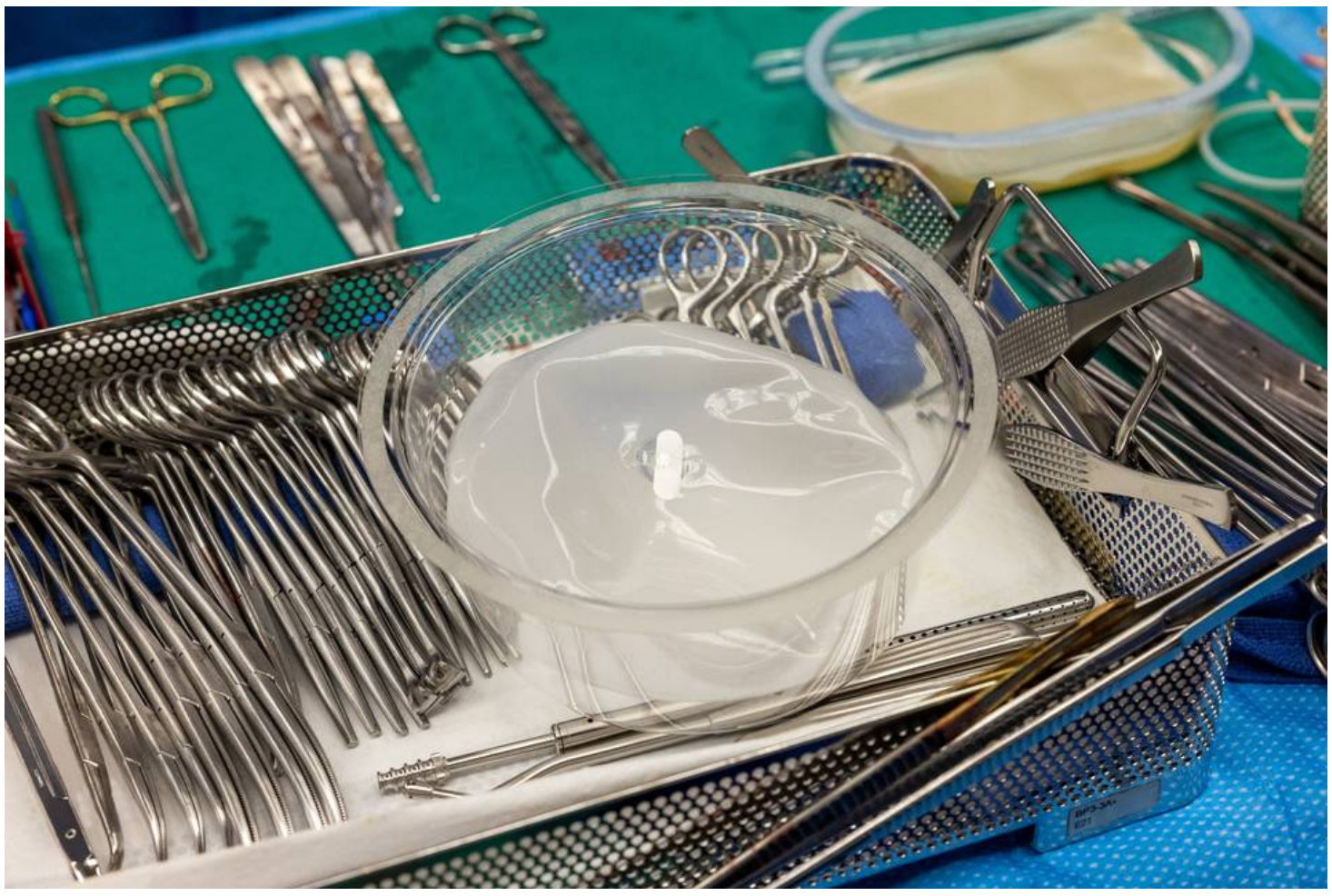
His doctors had to get creative.

On May 26, surgeons created what they called an “artificial lung,” a piece of equipment that could be placed inside Bauer’s body that moves blood to the heart and keeps oxygen pumping through his brain and organs.

Then surgeons removed his infected lungs but were faced with finding a way to keep

Bauer's heart from collapsing into the open space his lungs left behind, according to the release. Enter: breast implants.

"One of our plastic surgeons was very gracious to give us a rapid-fire course on the different types, shapes and sizes of breast implants, so we picked out a couple options and some of them were easier than others to mold inside Davey's chest, with the DD option being the best fit," Ankit Bharat, chief of thoracic surgery and director of the Canning Thoracic Institute at Northwestern, said in the news release.



Unsure how to keep Bauer's heart in place with his lungs removed, a plastic surgeon suggested using breast implants, according to a news release. *Northwestern Medicine*

As soon as the infected lungs were removed and Bauer's heart was stable, his body could fight off the infection, doctors said.

Within a day, Bauer was ready to be placed on the lung transplant list — and he found a match.

On May 28, the breast implants and artificial lung were removed and two new, if slightly used, lungs were placed back into his chest.

Bauer remained in intensive care for a few months before he was discharged to rehabilitation therapy in September, according to the release.

Bauer had two DD breast implants in his chest to hold his heart, coining the nickname “DD Davey,” he said. José M. Osorio *Northwestern Medicine*

With improving health, Bauer is also in high spirits as he stays in Chicago so his doctors can monitor his recovery.

“I plan to get a T-shirt made that says ‘DD Davey’ on it and change all my gaming profiles,” he said in the release. “While we don’t have definitive ways of proving my years of vaping caused my medical condition, doctors do know for a fact that vaping causes lung injury. If I could go back in time, I never would have picked up a cigarette or vape pen, and I hope my story can help encourage others to quit, because I wouldn’t wish this difficult journey on anyone.”

If you or a loved one shows signs of substance use disorder, you can seek help by calling the national hotline at 1-800-662-4357 or find treatment using SAMHSA's online locator.

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IRENE WRIGHT

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Irene Wright is a McClatchy Real-Time reporter. She earned a B.A. in ecology and an M.A. in health and medical journalism from the University of Georgia and is now based in Atlanta. Irene previously worked as a business reporter at The Dallas Morning News.

NATIONAL

‘Gas station heroin’ banned in 9 states. What is tianeptine and why is it dangerous?

BY **IRENE WRIGHT**
OCTOBER 13, 2023 10:56 AM

Zaza Red is a popular over-the-counter brand of tianeptine, now banned in nine states, officials said. *Florida Office of the Attorney General*

Dietary supplements containing the ingredient tianeptine are the subject of bans across the United States after health officials warned of the potential risks.

Florida Attorney General Ashley Moody became the latest public official to announce an emergency ruling on Sept. 21, banning the sale of tianeptine and changing its classification to a Schedule I controlled substance.

Tianeptine was already banned in eight states — Alabama, Georgia, Indiana, Kentucky, Michigan, Mississippi, Ohio and Tennessee — after warnings from health officials, Moody said.

From 2020 to 2022, more than 600 calls were made to poison control centers after exposure to tianeptine, resulting in five deaths, Moody said.

The drug remains on shelves in other states, and it’s still available online.

Here’s what you need to know.

WHAT IS TIANEPTINE?

Tianeptine, also known by its pharmaceutical names Coaxil or Stablon, was developed as an antidepressant drug used in Europe, Asia and Latin America, according to a study by the Centers for Disease Control and Prevention.

The drug increases the amount of serotonin the brain can take in, thereby decreasing the brain's physical response to stress, according to a 2001 study published in CNS Drugs.

Despite its use internationally, tianeptine was not approved by the Food and Drug Administration for use in the United States, citing the high risk that the drug could be overused or abused.

Tianeptine causes a similar high to opioids when taken in larger doses, Moody said, as well as similar overdose symptoms.

It's also just as addictive, especially among those already using illegal substances.

A 2018 study found that 63% of the tianeptine users included in the study were addicted to other things, as well as the dietary supplement, Vice News reported.

Unlike the other Schedule I drugs, tianeptine can be delivered to your door with a few clicks of a computer mouse or purchased after a walk to the corner store.

WHAT PRODUCTS CONTAIN TIANEPTINE?

Though tianeptine isn't approved for medical use, it's still sold as an ingredient in products marketed as dietary supplements online and in some gas stations and convenience stores in the United States.

It's sold under the names Pegasus, Tianaa or Zaza Red, among others, and is often referred to by its nickname "gas station heroin," according to Moody.

Tianeptine, also known as “gas station heroin” is a dietary supplement that mimics the effects of opioids, health officials say. *Florida Office of the Attorney General*

The supplements also list tianeptine under other names on the supplements.

Tianeptine sulfate, tianeptine sodium powder, tianaa, tianna green, tianna red and tianna white are all names for the same drug, according to the FDA.

The products sell the drug as a pill or powder, and the bottles say it provides energy and helps with depression. Websites selling the pills offer a warning that it can’t be shipped to the nine states with bans.

It’s also sold on the same websites as Kratom, an herbal pain reliever at the center of multiple wrongful death lawsuits, McClatchy News reported.

IS TIANEPTINE SAFE?

The short answer is no, tianeptine is not safe to consume in the form currently available.

But health officials would say it’s the dose of the drug that is unsafe, not necessarily the drug itself.

“Medical journals and reports to the FDA suggest that adverse events may occur when tianeptine is taken at doses higher than the doses prescribed in the country where the drug has been approved,” the FDA said in a news release. “Some people may have difficulty stopping their use of tianeptine and may experience withdrawal symptoms.”

The FDA noted cases where people abusing tianeptine alone, or with other drugs, experienced agitation, drowsiness, confusion, sweating, rapid heartbeat, high blood pressure, nausea, vomiting, slowed breathing, coma and death.

There is also little to no oversight of the $46 billion dietary supplement industry, Consumer Reports reported in 2021, meaning there may be other harmful things in the supplements that aren’t listed.

Dietary supplements don’t need FDA approval for sale, meaning it’s up to the states to monitor and control the types of products that can be sold.

The Florida poison control center received 15 exposure calls in the first half of this

year, Moody said, from users ranging in age from 23 to 58.

“Calls into the center are voluntary, so the number of cases likely exceeds those reported,” Moody said.

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IRENE WRIGHT

MCCLATCHY DC

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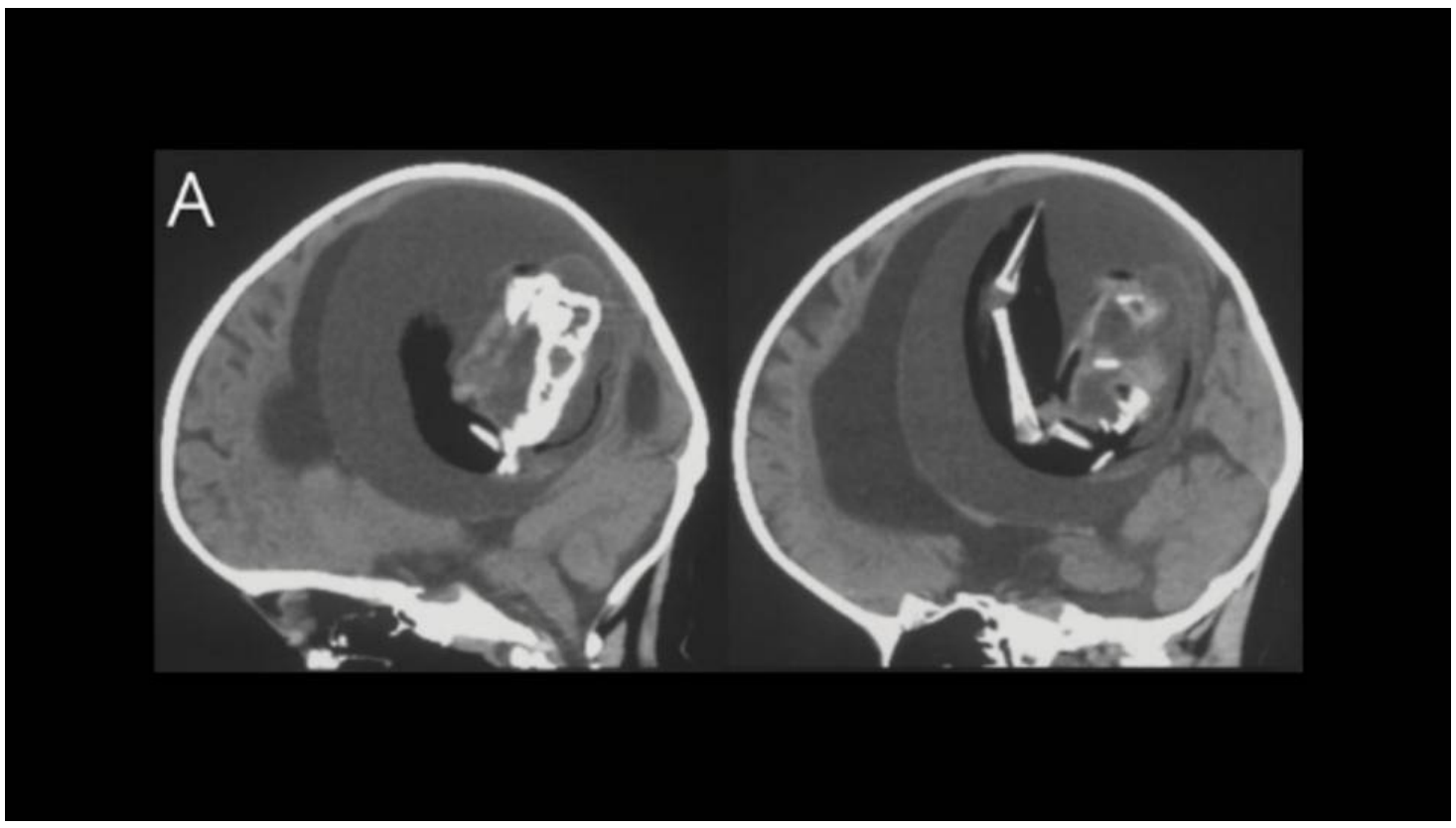
WORLD

1-year-old's unborn twin found inside her brain. Here's what neurologists did next

BY **IRENE WRIGHT**
MARCH 08, 2023 12:54 PM



Inside the 1-year-old's brain, doctors could see a spine and other bone structures. *Neurology*

A 1-year-old girl in China was having difficulty with her motor functions. Her head was enlarged, and she wasn't developing at the rate expected for a child her age.

Doctors decided to take a closer look, and when they took an X-ray of her skull, they saw bones in a sac inside her brain.

The case study, published in the scientific journal Neurology in December, said the phenomenon was an intraventricular fetus-in-fetu.

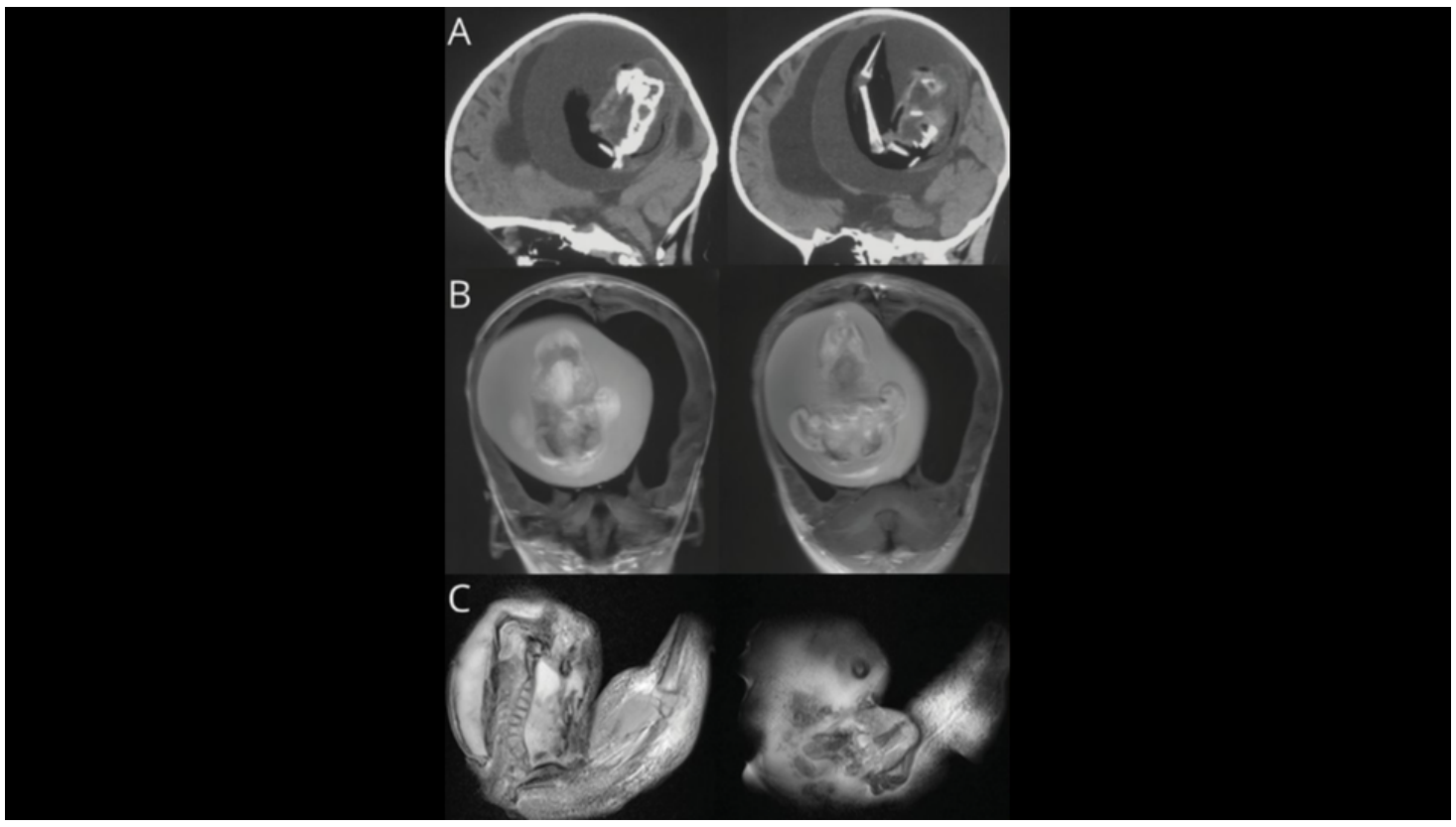
Fetus-in-fetu, sometimes called a parasitic twin, occurs when twins become conjoined in utero, but only one continues to develop. The undeveloped twin is often absorbed into the body of the developing twin.

But absorption into the brain is extremely rare.

Doctors decided the parasitic twin needed to be removed for the health of the 1-year-old.

What they removed was a fetus, about 10 centimeters long, with the beginning formations of arms and hands. The fetus had a spine, but remained extremely undeveloped. The doctors called it a "fetiform," a type of growth that resembles a fetus.

When they ran DNA tests on the growth, they confirmed it was the twin of the living girl that had been absorbed during a developmental process called neural plate folding, a step necessary for the structure of the brain and spinal cord. This would explain how the parasitic fetus ended up inside its sister's skull.



The parasitic twin was around 10 centimeters long and had arm and hand structures, the doctors said. *Neurology*

It might sound like something out of a horror movie, like the 2021 film "Malignant," where a parasitic twin controls the living twin from inside her head, making her kill on his command.

But, it's far from science fiction, and it has happened before.

A 1982 case report outlined a 6-week-old that had a similarly enlarged head. When they opened the child's skull, they found a 14-centimeter-long fetus inside with limbs, a torso, a head and other recognizable features. The parasitic fetus was removed, and the living twin was able to recover.

The doctors in the case of the 1-year-old girl did not share how she is doing now.

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IRENE WRIGHT

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Irene Wright is a McClatchy Real-Time reporter. She earned a B.A. in ecology and an M.A. in health and medical journalism from the University of Georgia and is now based in Atlanta. Irene previously worked as a business reporter at The Dallas Morning News.

WORLD

Tiny computer in woman's brain changed her life. Then she was forced to get it removed

BY **IRENE WRIGHT**
JUNE 07, 2023 12:43 PM

The 49-year-old Australian woman had seizures for years until a brain implant changed her life, researchers said. ROBINA WEERMEIJER VIA UNSPLASH

When Rita Leggett was 3 years old, she was diagnosed with severe chronic epilepsy.

She had unpredictable and violent seizures, making it impossible for her to lead what many would consider a normal life.

"She couldn't go to the supermarket by herself, and she was barely going out of the house," ethicist Frederic Gilbert, co-author of a case report on Leggett, told the MIT Technology Review. "It was devastating."

Leggett tried everything to manage her condition, but after testing a wide range of treatments with varying efficacy, nothing seemed to be successful, according to a May 1 case report published in Brain Stimulation.

That was until Leggett was 49 years old, and a group of researchers recruited her for an experimental clinical trial in 2010, according to the MIT Technology Review.

The trial tested a brain implant from the company NeuroVista that helped detect and alert someone if they were about to have a seizure, according to the case report.

The study, later published in The Lancet in 2013, enrolled 15 patients from around Australia who regularly had between two and 12 seizures per month.

The researchers surgically implanted a brain-computer interface, or BCI, into the skull of each study participant. A tiny computer and a grid of electrodes read neural activities in the brain and scanned for a neurological pattern that suggested a

seizure was about to occur, according to the case report.

SPECTACULAR BENEFIT

For Leggett, the implant changed her life.

“Most people had a reasonable benefit and some people had a spectacular benefit,” Lancet study author Mark Cook told Nature. “I don’t think anyone could have imagined that anyone could do so well from this device.”

Before the implant, Leggett had on average three seizures a month. Once the implant was in place, she was alerted when she was going to have a seizure. The alert gave her time to take a dose of clonazepam, a drug that treats seizures and panic disorders.

Over the course of the two-year trial, she didn’t have a single seizure.

“I felt like I could do anything … apart from obvious little things like jobs,” Leggett told researchers in the case report. “But I could drive, I could see people, I was more capable of making good decisions, not bad decisions.”

She grew to have an intense emotional attachment to the device. It gave her a sense of safety and security, she told researchers, and she believed she became one with the BCI.

“My device became as dependable as time itself. Your alarm clock that wakes you up in the morning to get you to work on time! Your appointments for that day!” she told researchers.

For two years, Leggett bathed in the newfound control she felt over her life.

Then, NeuroVista went bankrupt.

‘WOULD’VE DONE ANYTHING’

The company presented its findings to possible investors during the experimental trial, showing that seizures could be predicted and prevented, Cook told Nature. But, implanting a computer into the skull is an invasive procedure, and investors were uneasy.

Without funding, the company discontinued the trial, and because the experimental implant had only a three-year battery life, it meant it had to be removed.

“I wish I could’ve kept it, I would’ve done anything to keep it,” Leggett told researchers.

She tried to buy it, hoping that by purchasing the implant the company would let her keep it inside her head. She told researchers her husband was willing to take out a second mortgage on their house just to finance the purchase.

But the fight was lost, and Leggett was forced to get the implantremoved, according to the case report.

“I was the last person to have the device out,” she told researchers.

What followed was a mourning period. Leggett was thrust back into the life she was willing to get experimental surgery to escape.

She cried for her loss of independence and the self-doubt she now felt knowing she

could have a seizure at any time.

“Living without my device was very hard at first. I always felt like there was something missing, I’d forgotten or left behind,” she told researchers. “How will [I] cope and live without my trustworthy dependable part of myself?”

She was right back where she started, and she began having seizures again.

ETHICAL QUESTIONS

“Important ethical questions are raised in the case of this patient,” the case report authors wrote. “What are the possible moral rights and legal protections for allowing implanted BCI users to retain access to the therapeutic benefits available only through sustained and secure use of the device? Do companies or medical teams have a moral obligation to maintain any postoperative ‘new person’ emerging from a successful implantation of an AI brain device?”

The ethicists who examined Leggett’s case described “symbiosis,” or a relationship that is mutually beneficial to all interested parties.

For Leggett, the computer provided a medical service. For the computer, Leggett provided data that could be used to update, expand and improve the implant.

“In our case above, the concept of a postoperative de novo (symbiotic) person seems to be regarded as being less than a full legal person since the device company did not prioritize her preservation and dismissed the objections and resistance of (Leggett) to be explanted,” the authors wrote. “One relevant ethical question is whether this should have been the case.”

The authors introduced the concept of “neuro-rights,” an extension of patient and human rights that allows for the right to preserve “people’s personal identity and the continuity of their mental life from unconsented external alteration by third parties.”

Leggett felt like a new person, with a new personality, after she was implanted with the computer. When it was taken out, that person was gone.

The authors argued that by taking the implant out of her head, the company was violating the European Union’s Charter of Fundamental Rights, which states that “everyone has the right to respect for his or her physical and mental integrity,” according to the case report.

“If there is evidence that a brain-computer interface could become part of the self of the human being, then it seems that under no condition besides medical necessity should it be allowed for that BCI to be explanted without the consent of the human user,” case report co-author Marcello Ienca told the MIT Technology Review.

Ienca said it was the same concept as removing someone’s organ without their consent, according to the MIT Technology Review.

Years later, now 62 years old per the review, Leggett is still coming to terms with her immense sense of loss.

“I mean I know it’s been a while, but I still know what it did and how it worked and in a way if you think about it you can feel it still. It’s like it’s there but it’s not there,” she told researchers.

“A loss, a feeling like I’d lost something precious and dear to me, that could never be

replaced: It was a part of me.”

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