

April 29, 2025; Sorry, we left an implant in your brain

[BUMPER]

Julia Longoria (host): Our story begins in the late 90s.

SFX - Beep boop dial up

Jen French: March of 1998. the.com era, when the internet was coming about. It was really an exciting time to be in consumer technology.

SFX: You've got mail!

Julia: Jen French was working for a consumer tech business

Jen: It was laptops and, printers. a very young company

Julia: And her company was about to go public.

Jen: It was kind of a work hard, play hard type of lifestyle.

Julia: She worked hard to launch the company's IPO... and then?

Jen: We rented a house on the side of a ski mountain in New England.

Julia: She played hard. For Jen playing hard really meant playing.

Jen: Snowboard during the day and play poker at night and have lots of fun.

Julia: She's big on games and sports. She loves to sail. Loves to snowboard.

Jen: That weekend, there was a full moon, and if you've ever snowboarded under a full moon...

Glowy drone

...it's beautiful. Like the, the ski slopes just glow.

Jen: So, a dozen of us went down for the, what's called the midnight run. And 11 made it to the bottom and I didn't, I, uh, hit a patch of ice, went down a 40 foot embankment and hit a bunch of trees

CRASH

And, um, ended up face down in the snow. I don't remember much from that night. I have little spots of memory.

FLASH

Looking up at the full moon and crying for help and being really cold.

FLASH

being in an emergency vehicle covered in thermo blankets, shivering and not being able to move.

FLASH

waking up in the emergency room when they had put me in traction, that's when they try to pop your spinal cord back into place.

FLASH

MUSIC OUT

Jen: They came into a room and explained to me that I have a spinal cord injury and that I would be paralyzed for life.

Julia: The injury was at the base of Jen's neck.

Jen: So I could move like my arms, I could shrug my shoulders, uhhh, but I really didn't have any movement below that.

Julia: The prognosis was that she'd never walk again.

Julia: What did you feel at that, at that moment when you're, I mean, when it's sort of starting to hit the realization,

Jen: Um, well, it, it didn't, to be honest with you, I mean, I was in denial for a while.

Julia: It started to sink in in rehab. She was able to restore some of her hand movements but even when she finally went home 3 months later, she was still unable to do SO MANY of things she used to be able to do.

Jen: Oh my God, you name it. I couldn't get in and outta my house independently. I couldn't drive, I couldn't make myself food. I mean, dressing myself was a full on workout I mean, there would be days where I couldn't put my shoes on and I'd throw 'em across the room. I went through, uh, phases of denial and um, windows of depression

Julia: And Jen was always looking out for a cure. A clinical trial or experimental treatment that could give her hope of walking again.

JEN: At the time, stem cells were the big thing. But you know, I, I. I didn't understand all the biologics behind it, and if I don't understand something, I have a hard time jumping in. But, you know, I, I understood electricity.

Julia: Scientists at Case Western Reserve in Cleveland claimed they could implant electrodes inside the body and use electricity... to make paralyzed people walk again. Jen knew it was just a clinical trial at first.

Jen: Okay, we're gonna go down this new frontier and if it works, great. If it doesn't, at least I made my contribution to science.

Julia: But if the clinical trial proved that it worked, a company called NeuroControl was already standing by. They had acquired the rights to the technology and were planning to commercialize the device. To provide a PERMANENT CURE for paralysis.

Jen picked up her life in the northeast and moved to Cleveland.

Jen: The first procedure was seven and a half hours. I just remember the room being full of people. Cause it was an experimental surgery. So we were kind of training new people on, on the surgery so they implanted eight electrodes, in my back and my glutes and hamstrings and, and quads and hips.

Julia: The electrodes went under the skin right onto the muscle...

Jen: When you think about how our muscles move, uh, we send a command from our brain, it goes down our spinal cord, it goes out to the peripheral nervous system, and the peripheral nerves say, Hey, muscle, you need to contract. And it contracts the muscles.

But Jen's injury had severed the communication between her brain and her nerves on her muscles... so this new system of electrodes was kind of like a system of artificial nerves. Nerves that wouldn't be controlled by her brain, per se...

Jen: They give you a control box. It has all the brains, the circuit boards the battery power

Julia: It would be controlled by a remote control.

Pretty soon, it came time to take the new system out for a spin... to have Jen try and stand up by herself. It was a whole.. event.

Jen: My husband took off of work and he was there and my mom was there, my parents,

I get in position, press a button, wait a few seconds, and I hear a beep

SD BEEP

and it starts contracting.

SCORING

Jen: You could see like the contraction in your muscle. And that's the first time I had seen it in a year and a half. And that was, you know, that was just amazing, like, oh my god, you, you can make my muscles work again. This is, this is so cool. Right?

I mean, geez, being able to stand up and look down and all you see are your legs and you don't see these big braces around it or any other big supports. It's just you standing. I mean, that, that was amazing.

I don't think there was a dry eye in the room actually. I think it was, it was more of awe of, um, of science and technology, but also like, wow, it's, this is, this is real. Um, and it really works. This isn't a pipe dream.

SCORING OUT

Julia After the clinical trial ended, Jen took the device home with her. At least temporarily, she got her life back. She was able to get out of bed in the morning. Climb stairs. She could stand up at baseball games. She could even sail again.

All that was left to make the cure permanent was for the company, Neuro Control, to commercialize it. She was still waiting to hear about next steps... when she got some news.

Jen: I was implanted in 1999, and then in year 2001, I was on the NIH campus.

Julia: She was at a conference at the National Institutes of Health... which was one of the funders of her clinical trial. Some of the Case Western researchers she'd worked with were there.

Jen: At that conference, one of the, the main researchers came up to me, got on his knee and told me...

Julia: He got on his knee?

Jen: Yeah, he, well, he got down to my level and said, I need to talk to you.

SCORING

JEN: Neuro control went outta business. So the whole aspirations of this being commercialized went down the tubes. I just remember it hit me like a, like a brick. There were tears, I mean, it was a dark moment, you know?

Julia: Without a company to fund the device's future, Jen would be paralyzed all over again.

Jen: You know, it's like facing a spinal cord injury for your first time becoming paralyzed. What's next? Right? So that's the question that kept going in my head is what's next?

SCORING BUMP

Julia: This week...What happens when the life changing technology implanted deep inside your body... suddenly gets ABANDONED? I'm Julia Longoria. This is Unexplainable.

[THEME]

Julia: Does your device make a sound?

Jen: Yes. Oh yeah. Oh yeah. You have to, oh, hang on. Okay. Okay, let me turn it off. All right. So you're gonna laugh at this. one of the engineers, his kids were really young at the time, and he said, how can I make a distinct, a distinct sound so that people know when it's turning on so ok I'm gonna power it up now and and tell me if you recognize this beep beep beep tune.

Julia: I just hear like (singing) daa daa daa

Jen: Exactly. You know what song that is?

Julia: What is it? No.

Jen: DOH-RAY-ME.

Julia: Oh, oh. Like from, like from Sound of Music?

Jen: Yes. So, uh, so yeah, engineers always put their little fingerprint on things

Julia: Jen's remote controlled neuro implant is still with her. We were on video chat, I watched her use the device to get up and sit down a few times.

Jen: I know some people in the research world call it the Radio Shack device. Um, so probably some of your older listeners, it still looks like a product of the nineties.

Julia: Yeah. A Radio Shack device in every sense of the term, I guess

Jen: Yes, exactly. So I've been in this long-term clinical trial for 23 years. Um. Yeah, if you take start to finish, it'll be 25

Julia: When the company that was going to take her device to market went bankrupt... she and the team at Case Western Reserve got creative.

Julia: What, what did you do next?

Jen: The research team regrouped and, and took everything back into research. So that's how it became a long-term research study. Yeah. So it's under various grants actually. Most of them are government grants. The team in Cleveland is amazing to, to be able to still support this device. But I'll tell you that's, that was a window into, you know, the concept of abandonment.

Julia: Since the company Neuro Control went out of business in 2001, no other company has picked up Jen's device. About 350 people would have lost the life changing technology but the researchers at Case Western have figured out ways to provide versions of what a company would provide: they use old parts and keep applying for academic grants to keep the devices up and running in as many patients as possible.

Julia: Listening to Jen's story, like what was going through your mind

Liam: I mean, it's a funny thing to say, but Jen was basically one of the lucky ones

Julia: This is Liam Drew.

Liam: I arrived at Jen's story having spoken to several people who'd had neural devices implanted that had changed their lives much for the better, and then completely lost access to those devices.

Julia: These days, Liam's a freelance science journalist.

Liam: Having previously been an academic neuroscientist and I...

Julia: You were previously an academic neuroscientist?

Liam: Yes. I've been reporting on neurotechnology now for around eight years

Julia: I first learned of this phenomenon of abandonment from a piece Liam wrote in Nature magazine a few years ago... called Abandoned.

Liam: Abandonment has actually become the sort of.... The name for this problem. Maybe it's a fairly obvious name for it, but it, it's, it's been interesting to see that term become quite standard in the literature.

Julia: The first patient that Liam encountered with an abandoned neuro implant had a very different fate from Jen French's.

Liam: Her name was Rita Leggett.

SCORING

Julia: Rita wasn't paralyzed. Rita suffered from seizures.

Liam: Her life had really been defined by epilepsy for a long time. And by the end of her forties she was quite depressed and she was sort of anxious about leaving her home.

Julia: And then Rita had a device implanted in her brain that could warn her when a seizure was coming.

Liam: The device just through simply. Well, there's nothing simple about it. Just by warning her that a, a seizure was imminent and giving her that control that she could go take herself to a safe place, maybe take a dose of medicine that would make the seizure less severe, it gave her an, an unbelievable, lease of life. She, she actually met a man and got married. Utterly, utterly transformative. The very complex and unprecedented relationship that could form between a human being and, and, and a brain implant.

SCORING BUMP

But then the tragic end of the story was that although this device was very successful, the startup that was developing it couldn't attract sufficient funding to keep going with it.

Rita and her husband sort of fought tooth and nail to, to buy the device and somehow get support. But it was simply a case of, that's it, it's, it's over. You, you can, you can have it for as long as the battery runs, but we can't recharge it.

SCORING OUT

And as I've learned about more and more cases of this, what, what's, it's seemingly, I found it utterly shocking to begin with. And I think it, it probably is shocking to a lot of people, but it's often the battery that's the problem. Uh, something that simple. So the comp, I mean, I, I'm a biologist by training. I don't know a lot about batteries, but, um, companies are basically coming up with proprietary batteries and so if that's a unique part of the technology, then when the company goes all support for that battery system goes with it.

Julia: It's like, it's so simple. It sounds so dumb. Like you, you laugh you don't cry. Like I can't imagine having this like life changing relationship with a device just severed because you can't replace the battery.

Liam: Yeah. No, I, I, yeah, I was exactly the same at the beginning. I was just like, really? That's the issue. Rita, she had to travel to the hospital to return the, the external part of the technology...

Julia: because part of it was just still in her?

Liam: Yes. Yeah, the internal part remained in her brain. And, um, Rita had had to hand over the device to a stranger, and the stranger And so she just sort of left so disheartened, um, yeah. And, and the internal part of the device is still in her brain and that's quite a common thing. Quite often these devices that are left in people's brains can be incompatible with MRI scans. And so they can actually become a real problem. I think they've got slightly better in recent years, but, you know, just in terms of human costs, not being able to have an MRI scan because you've got some device left in your head or body from a trial, it is quite a price to pay for that.

Julia: When there's not even an upside if doesn't work anymore

Liam: Yeah, no, exactly. Exactly.

Julia: But Liam talked to another patient who was staring down the barrel of that same fate: having a device abandoned in his brain... because the company went bust and couldn't replace the bespoke battery.

Markus: (in german) It's a devastating pain.

Liam: Markus Bohle. Marcus lives in Germany, And he had an implanted nerve stimulator that treats cluster headaches, a debilitating type of headache.

Markus: (in German) I temporarily even struggled with suicidal thoughts.

Liam: He was sort of up to six to eight, one hour long excruciating headaches every day. In Marcus' case, the nerve stimulator is, is in his left cheek and it sort of intermingles with, with the nerve fibers that, that run to your face to help you control your face. And, and they're responsible, it seems for triggering these cluster headaches. And so if you can sort of zap those with electrical pulses, then that disrupts and sort of quells the headache.

Again, he just really felt like he got his life back with this device. The trial was a, was a great success, that the device was very effective. But cluster headaches are very rare, and so it's not a big market. It's a very exciting device, the company that developed this system has gone bankrupt and no one has access to this device anymore.

Markus: (In German): I'm an electrical engineer.

Liam: he's an electrical engineer by training and he has been for the last two or three years at the time, maintaining his own device.

Julia: Maintaining his own device. What does that mean?

Liam: So again, it was this proprietary battery. Um, so it wasn't a case of just sort of going to the shop and buying a new bunch of AA batteries. Um, it was this very rare battery, uh, and he initially scours the internet and he finds a company in America that will sell him a battery of this nature. And he has sort of has to convince the insurers that he is qualified to do this but he gets a battery from America. It replaces it, it works. That battery runs out. He goes back to the American company, they've stopped making it. So he sort of has to scour the internet again. And he finds a company in China who are willing to make a battery of this nature. And so he's able to maintain the device.

SCORING OUT

Julia: There, something very like, I don't know, like 2025 dystopia about how like this man is forced to like, hire a Chinese company to just DIY, his own medical device

Liam: Yeah.

Julia: just like, again, laugh so you don't cry

Liam: Yeah,

Julia: Really wild.

LIAM: In his case he's been able to maintain it. But for many of these people, it was just this sort of brief few years of respite from a sort of life defining condition.

Are you still there?

Oh dear, what's going on here?

Julia: After the break, how to combat abandonment...

Liam: Oh, come on.

[BUMPER]

[MIDROLL]

Liam: Hello.

Julia: Hello.

Liam: I think my computer just crashed. I, I don't know. Um,

Julia: Oh, fun!

Liam: yeah.

Julia: um, speaking of technology abandonment...

Liam: Yes, exactly. Exactly.

Julia: Um great so... um I think we have this idea, or I certainly have this idea somewhere deep in my psyche that, if we have a new miraculous technology, health technology that works, like we just assume, some of us assume that the economics will just kind of work themselves out. Like the good ideas are gonna rise to the surface. but it feels like your reporting shows like the economics don't always work out, even if it's a, a technology that works.

Liam: Yeah, certainly the cluster headache device and the epilepsy warning system, were both clinically really effective. It was business issues that sank both of them.

Julia: Do you have a sense for what, what a company needs to succeed watching the ones that didn't?

Liam: No, I think that's beyond my pay grade. Um,

Julia: <laughs> Same...so....

Liam: Well..yeah..

Julia: It's a big feat to bring a pretty high maintenance technology... to hundreds of people without breaking the bank.

Liam: The first person who gets one of these devices implanted in them will typically have the full attention of the entire team, right? The engineers checking that it's working, the neurosurgeon, the clinical team, the nurses and doctors, the scientists checking the outputs of it, all of them in the room, you know, troubleshooting, willing them on-And then as it becomes a product, you basically want it to be something. I mean, it needs to be something that, you know, someone with...

Julia: It is self-sustaining.

Liam: Yeah. Basically self-sustaining and sort of something that someone can program themselves and use themselves. And, and that's, that's a real challenge in this field: scalability.

Julia: It seems like it takes a village almost to get these medical devices up and running. But then you don't want to pay a village to keep them running.

Liam: Basically. Yes.

Julia: The "village" that makes neuroimplants possible... knows that their industry has a problem. Liam went to a sort of convening of the village after his story in Nature magazine came out.

Liam: A year after it came out, I went to a meeting at the Royal Society and there was a session that was dealing with how we can protect people from abandoned devices. And I sort of sat down and the, the chair, a neurologist from Florida, introduced the panel, and then-he said if anyone really wants to know the background of this session, they should read Abandoned by Liam Drew

Julia: In this conference room, full of doctors, nurses, patients, and industry, Liam's reporting helped spark a conversation about what can be done about the problem of abandonment. One big idea that comes up a lot, says Liam, is the idea that some kind of plan has to be in place in case a company goes south.

Liam: I mean the tricky problem with companies going bust is that no company plans to go bust. the company that I reported on that did go bust, I spoke to one woman who'd had new vectra's spinal cord stimulator implanted. And it was when she went back to the surgery to have her stitches removed, that she was told that the company had gone bust. The company had given no warning whatsoever. Their devices were being implanted, you know, essentially on the day they went bust. So there was no sort of warning that they were about to go belly up and not be able to support these devices anymore. So sort of short to medium term support, just to sort of cushion the fall of the, of the device being no longer available, um, feels like one part of it.

Then, the harder issue is what do you do about the long term. Can't they put money in an escrow account? Can they set up a sort of non-profit parallel organization? Can they take out insurance? Everyone wants that support to be in place. But I think if you're a business person dealing with a startup where margins are small they hear those plans and they just think that's expensive. That's just a big chunk of change for a small startup to take on. And so I, I remember very clearly one business person just saying it's not gonna change unless there is legislation that demands change.

Julia: But even patients are hesitant about legislation. They don't want to have barriers to entry either for startups that go out on a limb and support life saving devices.

Liam: It does have to work from a business perspective, 'cause if it becomes too expensive to develop new devices, you are not gonna get the new devices that could help people. So –

One other thing I will say, just as, I dunno, maybe it's a bit gloomy, but another layer of this is that we all know from our phones for example, how quickly technology changes. Like a, an iPhone 16 compared to an iPhone 2 is, is, is night and day. Whereas, you know, an aspirin is an aspirin and it was a hundred years ago, and so how do companies keep supporting sort of, you know, version one, version two of their technology when they're on version 16? 'cause, you know, we're all expected to sort of not use an iPhone two or three anymore. But if your iPhone was implanted in your head and you didn't have any say about what iPhone you were gonna use, that's a different issue. So I think one of my biggest concerns about this is that we've seen an absolute mushrooming of neurotechnology companies so I think just that, that investment and that will to create good products is, is great. And hopefully that will. Benefit people who need them. But at the same time, it's, it's potentially gonna create a crowded marketplace in which there will be winners and losers and we'll see issues of this nature.

Julia: So it seems like, uh, people on all sides of this village that, um, make a, a medical device possible agree that, that there's a problem.

Liam: Yes.

Julia: What is the solution to the problem? Is there one?

Liam: I don't think we know what the solution is yet. It's, um, everyone who tries to create these devices is trying to do a good thing.

SCORING

You know, it takes years, decades from an idea through initial studies, through larger studies. You know, it literally takes decades to bring a product to market. In my experience, everyone I've ever spoken to in this field is incredibly passionate about helping people, and that's what drives them. So the idea of sort of helping them. And then not, is really distressing. Um, uh, that was most evident in the Case Western team, which has just kept supporting people. just sort of finding a way, you know, sort of talking to insurers, talking to the hospitals, just making it work.

Julia: Why is it so thorny? Like fe it feels like everyone has good intentions from what you're saying. Like people have thought about this so deeply. People who have all the personal stakes in the world can't, still can't offer up a solution. Um, I wonder why you think it's so unanswerable.

Liam: Um, I think everyone would just like it not to be a problem. Um, you know, I mean, everyone's ideal version is that you sort of come up with a wonderful piece of medical technology and your company is de facto a huge success and you support people using it for the rest of their lives.

SCORING OUT

SD - TAPE OF JEN'S DOH-RAY-ME

Jen: Do I have a relationship with my device? I absolutely have a relationship with my device. I take it everywhere with me. I use it every day and, um, and when it doesn't work, it's like I'm paralyzed again. It's like this loved one that you're missing, you know?

Julia: I'm just curious, like, this is a very silly question, so feel free to disregard, but like, do, do you, do you, does it have a name? Like do you, I don't know, do you like find yourself, um, personalizing the, the device? I, I, I'm someone who like names my cars and things like that, but I, I'm just curious, does it have a name?

Jen: Well, no, Julia, I haven't gone that far. I haven't

Julia: Okay.

Jen: I haven't put eyelashes on

Julia: Fair, fair. You're not quite as goofy as me.

Jen: No, I wouldn't call it goofy. It's just, it's, it's my box. And, but I'm also, maybe, maybe that's just my way of, um, subconsciously keeping a little bit of separation because I know that at some point in my life, I'm gonna have to give this back, you know, and I don't wanna..

Julia: Hmm.

Jen: Get too attached to it, even though I know I am.

Maybe it's, maybe it's a subconscious thing on my part

SCORING IN

JEN: When we're looking at all of the federal funding that is being cut off, all of the funding from National Institutes of Health, brain Initiative, you name it, um, you know, their funding has been dropped considerably and just wiped clean with no consideration of people in clinical trials. Right now we don't know.

I mean, I live every day with the possibility // of // being paralyzed again. Um, you know, I've had, over the years, I've had the whole system fail twice. Um, and twice I've been, you know, paralyzed and then waiting for them to get grant funds so that we can reimplant

Julia: Knowing what you know now, um. If you could time travel back to, you know, the nineties before you moved to Cleveland, before you got this device implanted, knowing

like the uncertainty that you're facing, like, would you stop yourself from, from going through with it?

Jen: No way in hell. No way in, no. It's been, you know, it's been an incredible journey. Um, I wouldn't have taken this career path if I didn't get implanted. now I'm in the neurotech business. So, uh, I, I run a nonprofit called Neurotech Network that focuses on education and advocacy of neurotechnology devices, therapies, and treatments. And it really is a labor of love. I wouldn't have even gotten into this field if I hadn't gotten implanted. I, who knows where my career would be. Um, so I cherish what I do. I cherish being able to learn so I, I wouldn't change a thing in the past.

SCORING BUMP

You can learn more about Abandoned Neurotechnology in Liam Drew's piece *Abandoned* in *Nature*. There's a link in our episode description. Audio clips of Markus Bohle in German were courtesy of *Nature*.

This episode was produced by me, Julia Longoria. We had editing from Meradith Hodinott, who also runs the show. Mixing and sound design from Cristian Ayala. Fact checking from Melissa Hirsch. Music from Noam Hassenfeld. Jorge Just is our editorial director.

And Byrd Pinkerton muttered to herself "Everything is legal in New Jersey" before shoving the note in her pocket and turning around.

Thanks as always, to Brian Resnick for co-creating the show. And if you have thoughts about the show, send us an email! We're at unexplainable@vox.com. And you can also leave us a review or a rating wherever you listen. It really helps us find new listeners.

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