Linda (LJ) Fullerton’s medical horror story began with the most innocent of accidents—she bumped her head on the doorframe of her car as she was getting out. This was in 1996 when she was 41 years old and a computer hardware salesperson. “It stung a bit for a few moments and I thought nothing else about it,” she said.

However, she started to get headaches, and a large lump (a haematoma, or blood clot) appeared several days later. She took some painkillers and her doctor said it would take a month until the swelling went down.

But the very opposite started to happen: the swelling got larger and the pain increased. Eventually, her doctor ordered a CAT (computer axial tomography, or CT) scan—but the proper contrast medium hadn’t been ordered and no skull fracture could be seen.

Over the next few weeks, LJ went to her local hospital emergency unit twice and was sent home on both occasions. She had X-rays, saw a neurologist, went to a pain clinic and was examined by a neurosurgeon, as well as visited her own doctor several times, but there was no respite from the pain. “I was given every painkiller known to man, none of which helped,” says LJ, now 57, from her Rochester home in New York.

Despite the constant pain and lack of sleep, LJ kept up her work and missed only one day while clocking up a 45-hour week. But this all came to an abrupt stop almost exactly a month after she bumped her head. She was at her boyfriend Arnold’s house and suddenly had difficulty walking. Arnold contacted LJ’s doctor, who said she should sleep through the coma.

The following day Arnold dragged her—rather than lift her—to the hospital and another CAT scan was organized. This time the radiologist used contrast medium and to his horror saw a white mass in the cerebellum (the small area towards the back of the brain). The neurologist announced he would have to perform brain surgery the following day, but then, on reviewing the scans, said he would need to do an emergency procedure that night as he doubted LJ would survive until the morning.

LJ’s brain was so swollen with fluid that the surgeon had to insert a drainage tube. The skull bone was full of holes and the base had been eaten away from a bone infection known as ‘osteomyelitis’. The original haematoma had also become infected by two forms of streptococci and a staphylococcal bug.

“If the doctors had only ordered a blood test when I was having so much pain, they would’ve seen that my white blood cell count was in triple digits. They could have given me antibiotics which may have killed the infections, and I never would have needed the horrible surgery,” says LJ.

After the operation the hospital put her on a course of three strong antibiotics before sending her home with an IV drip implanted in her arm. LJ developed an allergic reaction to one of the antibiotics, and she was covered head to toe with a horrible rash and had trouble breathing.

By the following March, four months after she had had the initial bump that started it all, LJ felt that she was finally well enough to return to work. But a few days before she was due to go back, she started having horrible pains in the back of her neck and head. “It was very frightening, and it felt like something was eating away at my spinal cord. I thought that the osteomyelitis was back again,” she recalled.

Again, doctors couldn’t find anything wrong, so this time LJ decided to do her own detective work. She started surfing the web and discovered that one of the best tests for bone infection is an MRI (magnetic resonance imaging) scan using contrast.

The hospital resisted, but as LJ later said, “I was in no mood to put up with incompetence again.” She had the scan and as she says, “I saved my own life this time.”

The MRI revealed that a blood clot had developed in her brain in an area that was inoperable. Faced with no other option, she agreed to take Coumadin, the marketing name for warfarin, or rat poison. The drug did the trick, although the surgeon was quick to take LJ off it as he had lost another patient from a brain haemorrhage caused by the drug.

The New York State Medical Misconduct Board investigated LJ’s case, but twice found her primary-care physician not guilty. She was told her case was very unusual and complicated, so it was unreasonable to find any of the carers guilty.

Since December 1997, LJ has been unable to work and is permanently disabled. She barely sleeps because the pain is still too severe, yet despite all of that, she says she is not bitter or angry.

Instead, she wants her story told so that others may be more vigilant and not just go along with what the doctor says. “People—and especially women—are dying every day because doctors don’t take their medical problems seriously enough. If Arnold wasn’t there, I would be dead; if I hadn’t taken charge later, I would have been dead a second time.”