It’s one of those things that’s only supposed to happen in a bad movie. A mother, whose child has been sick for much of his young life, keeps taking the child to doctors who have trouble coming up with a diagnosis; when they do, it seems to be the wrong one.

The mother takes her child from doctor to doctor trying to find one who can help, and that’s when the story really takes off. The child, says the next doctor, is fine, if a little depressed. It’s the mother who has the problem—who imagines these diseases for her son because she enjoys the attention it brings her. There’s even a medical name for it—Munchausen syndrome by proxy (MBP), and it’s not pretty by any name.

Or at least that’s what Connie Worthen discovered. Her son, Branson, was eventually diagnosed with common variable immune deficiency, but not before Connie was told she was committing Munchausen by proxy. “If you’re a parent, it’s about the worst thing that you can imagine happening,” she says.

She has since discovered that other parents of children with primary immune deficiency diseases (PIDD) have experienced the same thing. Their children’s problems were so difficult to diagnose and so baffling to even experienced physicians that the parents were suspected of Munchausen by proxy. Not surprising, the number of such misdiagnosed cases are unknown. There aren’t even any good statistics on Munchausen syndrome by proxy or its more common sibling, Munchausen syndrome, which involves fabricated illness for oneself. But, Gary L. Malone, MD, a psychiatrist who is the medical director of behavioral services at Baylor All Saints Medical Center in Fort Worth, Texas, says the misdiagnosis is not an unusual occurrence.

“Some doctors want a simple, take-home message,” says Dr. Malone, whose practice includes patients who have been misdiagnosed and have suffered mentally as well as physically. “But in cases like these, there’s not a quick, easy diagnosis. And some doctors don’t like to not know what’s wrong with patients.”

Defining Terms

Munchausen syndrome is mental illness in which someone acts as if they have a physical or mental disorder, when they have actually caused the symptoms themselves, according to information from the Cleveland Clinic. This is not a con or a scam; people with Munchausen syndrome are genuinely ill, not physically but mentally. They have a need to be seen as ill or injured and are even willing to undergo painful or risky tests and operations in order to get the sympathy and special attention given to people who are really sick.

Munchausen syndrome by proxy describes a pattern of behavior in which care providers deliberately exaggerate, make up or even induce physical and psychological problems in others, usually (but not always) their children. It’s a form of child abuse, say physicians, that often includes more common behavior like physical or sexual abuse, but where the parent also commits the acts for the attention he or she receives.

The disease is named for Baron von Munchausen, an 18th-century German soldier who exaggerated stories about his life. The exact causes of Munchausen and Munchausen by proxy are not known, but researchers believe biological and psychological factors play a role. Some theories suggest that a history of abuse or neglect as a child, or a history of frequent illnesses requiring hospitalization, might be factors associated with Munchausen syndrome. Even less is known about Munchausen syndrome by proxy. Sometimes, but not always, a care provider
performing Munchausen syndrome by proxy is a well-educated and overly attentive mother who is solicitous of medical staff and able to speak medical terminology. She is always willing to change doctors and hospitals, asks for specific procedures and invasive and painful treatments for the child, is resistant to new diagnosis, and gives incomplete medical histories.

Doctors think both syndromes are extremely rare (although they do seem to make regular appearances on TV shows). Despite the lack of reliable statistics, Vali Hawkins Mitchell, PhD, the executive director of the Kirsha Foundation in Richland, Wash., says that psychiatrists and psychologists who see Munchausen and Munchausen by proxy in a clinical setting are beginning to think both may be more prevalent than previously thought, due to what she calls their inherent covert nature. “Just as immune deficiency is now more clearly recognized, as are other disorders that were once not diagnosable like tuberculosis, consumption, diabetes, and cystic fibrosis, Munchausen by proxy is now on the radar,” she says.

Looking for a Diagnosis

So what’s a mother to do? Because, as Worthen and Kelliann Connor, who has two children with PIDD, learned, they each fit the Munchausen by proxy profile.

“It got to the point where I was kind of leery to even tell the whole story,” says Connor, a pharmacy technician whose older daughter took several years to be diagnosed and went through the gamut of physicians and tests. “I got so used to not being believed that I started to think the new doctors wouldn’t believe me either.”

In fact, says Dr. Malone, some parents (as well as immune deficiency patients themselves) even give up going to a doctor, once they’re convinced no one will believe them.

What causes this misdiagnosis? Doctors Malone and Mitchell say there are several reasons, one of which stems from the best of intentions. Most physicians genuinely want to help the child, and their assertion of Munchausen syndrome by proxy is done to protect the child when they can’t find anything else wrong. “There are always two sides to a story,” says Dr. Malone, “and the last thing the doctor wants to do is to feed into a hoax.”

Yet, that being said, physicians do sometimes mistake primary immune deficiency, which is relatively rare, for Munchausen syndrome or Munchausen syndrome by proxy, which are rarer still. Sometimes this is attributable to inexperience, since most physicians will see few, if any, cases of either during their careers. Some of it, meanwhile, is just part of the way medicine is practiced, says Dr. Mitchell. “Most caregivers, who have less than a few moments with the patient, will eliminate the obvious, categorize the simple, and avoid the time it takes to listen with a critical ear for the most subtle of messages about immune deficiency or Munchausen by proxy,” she says.

“This is not necessarily the fault of the caregiver as much as it is simply economically predictable.”

And sometimes, says Dr. Malone, it’s a mistake, whether from arrogance or overwork or the too common need for doctors to have an answer for every case they see. “Some doctors,” he says, “always have to be right.”

All of which means it’s up to the parents to persevere. “You are your only advocate for your child,” says Worthen, who has two other children.

This is much the same advice that Doctors Mitchell and Malone offer. Parents must:

- Educate themselves about what’s wrong with their children. It’s not enough to tell the doctor the child is sick. Know the symptoms and know what they mean, such as the relationship between sinus infections and immune deficiency.

- Understand that doctors are human, and that they make mistakes just like anyone else. “Doctors are your consultants,” says Dr. Malone. “Use them as consultants, and use them for what they are capable of doing.”

- Realize that they—and not the doctors—are the people who must make the decisions about treatment and care. Be patient, persistent and document everything.

According to Dr. Mitchell, in the end, perseverance pays off. In one case, a child seemed to suffer from recurring pancreatitis. The child was brought to a clinic 14 times and received 14 diagnoses. Eventually, the mother was assessed for Munchausen syndrome by proxy. Her child would have severe symptoms at home, but seemed fine when the child saw a doctor. It wasn’t until the 2-year-old vomited on several visiting physicians and remained unconscious that the doctors decided the child was truly sick.

“My general rule of thumb,” says Dr. Mitchell, “is that mothers do know what is going on with their children better than the caregiver’s four-minute intake interview. I think everyone needs to know that MBP is real and heinous, and so is [immune deficiency]. Both need time, attention, and subtle listening and communication skills that many care providers and patients may not have developed, especially under duress.”

It’s a rule of thumb that parents like Worthen and Connor understand.