

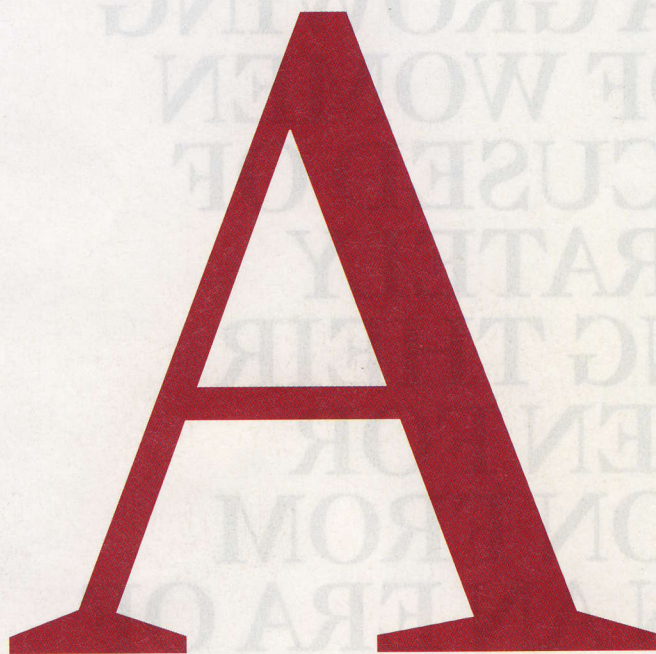


IN MOTHERS WE DISTRUST:
*Kelly Savage was tried and acquitted
of harming son Austin (center).*

**CALL THEM THE
MUNCHAUSEN
MOTHERS. A GROWING
NUMBER OF WOMEN
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PATIENT ADVOCACY AND
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THERE'S NO END IN SIGHT
TO THIS HOTLY
CONTESTED DIAGNOSIS.**

Unusual Suspects

BY PAMELA WEINTRAUB
PHOTOGRAPH BY PHOEBE ROURKE GABRIEL



AUSTIN SAVAGE WAS BORN THE YOUNGEST of four in Sierra Vista, Arizona, in 2002. He fell ill with pneumonia at one week of age, and landed in a hospital incubator. After he came home, he cried inconsolably, threw up his food, and barely gained weight. "I'd raised three other healthy children," says Kelly Savage, his mother. "I knew something was wrong."

While her husband, Buddy, stayed back in Sierra Vista, Kelly and the kids left for Tucson, where a top-notch medical center could drill down. Soon they found the problem: a case of acid reflux so severe that doctors said Austin must be feeling pain equivalent to a heart attack. So began a marathon of surgery, feeding tubes and special formulas. "It was scary," Savage says.

Then Buddy got a job near a major hospital in Fort Worth, Texas, enabling the family to be together, at last. Little Austin arrived with a mountain of medical records. By then 9 months of age, "he had constant, watery diarrhea and weighed as much as a 3-month-old. You could see every bone in his body," Kelly Savage recalls.

Desperate, the Savages reached out to local doctors, eventually requesting that nutrients be delivered intravenously,

despite damage to liver and kidneys that might result. "The doctors had no answers," says Kelly Savage, who worried that her baby might die. One doctor arranged for Austin to enter Fort Worth's famed Cook Children's Hospital in March 2004. Alone in the room with him, Kelly noticed an air bubble blocking his feeding tube, trapping gas in his stomach and preventing formula from getting through. Sensing her baby's pain, she sucked out an ounce of formula and the trapped air bubble beneath. "I planned to replace the ounce later," she states.

But she would never get the chance. Already suspect in the eyes of her new doctor, she'd been placed in a hospital room wired for surveillance, and now her accuser had "proof." Based on the video, the doctor charged, it was clear Kelly was stealing Austin's food, intentionally starving him because she craved the excitement of hospitals. Kelly Savage might have even killed Austin, all in pursuit of a bizarre form of child abuse called Munchausen by proxy (MBP), in which a parent—almost always a mother—exaggerates a child's symptoms or actually induces illness so she can swoop in to the rescue, thereby gaining attention and a special bond with the child's M.D.

That very day child protective services arrived to take Austin and his siblings into custody. In foster care, Austin refused to eat, stayed bloated, and had explosions of diarrhea. Finally the children, even Austin, were allowed to come home only if Kelly stayed away. With Austin's health at the precipice and her family ripped apart, she lived at a hotel and studied medical records, preparing for her day in court. "I swapped with my friends from church. I watched their children and they watched mine so my husband could go to work."

The Savage trial, in May 2004, lasted just two days. After expert witnesses combed through the medical records, dismantling the case against her, Kelly Savage was finally fully exonerated in January 2005. "It was a nightmare," she says. "We were too scared to take any of our children to the doctor until 2006."

A CONTROVERSIAL SYNDROME

THE VERY IDEA OF MBP IS DIFFICULT TO GRASP. CHILD ABUSE, of course, is a sad but well-known occurrence. That some mothers abuse children by poisoning or starving is beyond refute. But in Munchausen by proxy, hundreds of women a year in the U.S. alone are said to knowingly fabricate or induce illness in their children to garner a doctor's love. Whether the physician is male or female doesn't matter, says psychiatrist Herbert A. Schreier of Children's Hospital Oakland in California and co-author, with Judith Libow, of the influential book *Hurting for Love*. "These mothers are seeking a reparative relationship because they felt they weren't valued in their family of origin," Schreier states. "The mother becomes a 'perfect' mother in a perverse, fantasized relationship with a symbolically powerful physician." This motivation, he believes, is what differentiates MBP from ordinary medical abuse caused by anger, incompetence or neglect.

Given the abundance of accusations on the one hand and the outright strangeness of the syndrome on the other, MBP has become one of the most hotly contested psychiatric diagnoses in the country. On one side of the debate are psychia-



trists, psychologists, and plenty of social service agencies who say these cases occur regularly. They route them out when children are absent from school, or where mothers frequently change doctors or move. "Most cases go unrecognized," says University of Alabama psychiatry professor Marc D. Feldman, author of *Playing Sick*, who's popularized MBP in the medical press. "Perpetrators have borderline personality disorders and maladaptive ways of handling stress," he contends. "They have a hazy sense of identity, and compensate by creating the persona of mother of the year."

On the other side of the argument are wrongly accused mothers and the experts who have analyzed their cases, fighting for them in court. "I have seen mothers accused of MBP simply because physicians disagreed about the medical management of their child," says Portland psychologist Loren Pankratz of Oregon Health & Science University. An authority on the psychology of deception and author of the book *Patients Who Deceive*, Pankratz calls MBP "vastly overdiagnosed."

"There's virtually no empirical evidence that it exists as a syndrome," states New Hampshire psychologist Eric G. Mart, who has deconstructed the theory in the book *Munchausen's Syndrome by Proxy Reconsidered*. "Controlled and blinded studies have never been done."

The controversy pits doctors against mothers—an irony giv-

RUNAWAY: Mimi Reiser, 16, left home and married young rather than be forcibly separated from her mother, Terri, who was accused of harming her.

en that the crux of the theory is the mother's desire for physicians' approval and nurturance. A changing zeitgeist fuels the dispute. Patient empowerment, dissatisfaction with managed health care, and the intensified face of motherhood conspire to escalate standoffs between the medical establishment and parents. Assertive, demanding, and well-informed, mothers increasingly challenge doctors as a matter of course.

When a child stays sick and no one has an answer, relationships can turn sour, even adversarial. "Mothers who argue with doctors or seem challenging have been accused," Pankratz says, "as have those with children who are hard to diagnose or treat. Since mothers with chronically ill children usually have very strong views about treatment, there's a huge pool of candidates at risk."

BRITISH BACKLASH

THE MUNCHAUSEN BY PROXY STORY STARTS ACROSS THE Atlantic, where British physician Richard Asher described a group of wanderers who trekked from hospital to hospital fabricating complaints. In 1951 Asher named the condition Mun-



chausen syndrome after Baron von Munchausen, whose travel and military adventures spawned a series of fabulist tales.

It wasn't until 1977 that the British pediatrician Roy Meadow, writing in the journal *The Lancet*, identified mothers he said were causing or fabricating their children's illnesses. The mothers were coldly and intentionally using the children as "proxies," he theorized, taking them to doctors to get the attention they themselves craved.

People found it hard to believe this argument until Meadow's pediatric colleague, David Southall, videotaped suspects, unbeknownst to them. The most shocking Southall tape showed a woman smothering her baby with a piece of plastic wrap, then running out to summon doctors whenever his breathing stopped. Though some of the tapes were later questioned, and suspects including the woman who smothered her baby were actually psychotic, here at last was evidence of mothers doing harm.

Meadow and Southall later spent decades on the Munchausen scene, examining patient records, then using statistics, video surveillance, and the "separation test"—in which a child is removed from a suspect parent and monitored for improvement—to identify MBP perpetrators and testify against them in court. To bolster cases when evidence was slim, they brandished a profile of the classic perpetrator—a seemingly caring mother with great knowledge of medicine, especially

CAN 15 DOCTORS BE WRONG? Ron and Mannie Taimuty-Loomis were accused of sickening Ezra, 10 (center) and Symia, 4 (at right). Adia, 8, is at left.

the illness at hand, who cultivated doctors, and was intensely involved in her child's care. Thousands of sick British children whose mothers fit the profile were removed from their homes over the course of 25 years.

One mother caught in the frenzy, attorney Sally Clark, lost two children to sudden infant death syndrome in 1996 and 1997. After Roy Meadow testified that the chance of two such deaths was 73 million to one, Clark was convicted of murder and sentenced to life in jail. But Meadow's calculations were wrong—he'd literally made mistakes in math. The correct statistic was 200 to one, a world of difference to the court.

When Clark won her appeal in 2003, it was as if the blinders came off in Great Britain. Excoriated for skewed statistics and the by-then discredited profile (mothers of genuinely sick children are often intensely involved in their children's care), Meadow almost lost his medical license and soon after, retired. Southall too came under fire after accusing Clark's husband, Stephen, of smothering his sons. The accusation was based on no more than Southall's impression of Stephen on TV.

For months, stories of wrongly accused parents rang through

the British tabloids. This was junk science, members of Parliament and the British medical establishment ultimately declared.

AMERICAN LANDING

BRITAIN'S MBP-BACKLASH NOTWITHSTANDING, THE DIAGNOSIS is flourishing in the U.S. One case considered classic by Herbert Schreier is that of Coral Gables, Florida, mother Kathy Bush. Her daughter, Jennifer, spent 640 days in the hospital and underwent 40 operations, including removal of her gall bladder, appendix, and parts of her intestine, from ages 2 through 9. As the tireless advocate for a chronically ill child, Bush appeared with Hillary Clinton in her quest for health-care reform—before being convicted of making Jennifer sick by infecting her feeding tubes and giving her damaging drugs in 1999. She served three years in jail.

Bush has always maintained her innocence, but Schreier isn't impressed. He sees Bush and other such mothers as impostors devoid of feeling for their children. "The purpose is not to kill the child but to keep her sick, so that the mother can be in a relationship with the doctor, who would recognize her devotion, knowledge, and sacrifice," he states. As for the doctors, Schreier says they're routinely fooled by Munchausen mothers, "who may be issuing a dare, a challenge of who can outsmart whom."

No one has done more in recent years to ring the alarm than Louisa J. Lasher, a former child protection worker from Georgia now running the only forensic service devoted exclusively to MBP. She first learned of it, she says, when a mother she investigated made her daughter appear ill by painting her panties with blood, leading to unnecessary procedures. Soon Lasher was running workshops and training others to look for signs.

Today, when child protection agencies want to train case workers, they turn to Lasher. With her slide show, videos, and experiential exercises, she's taught thousands of case workers in dozens of states her investigative techniques and views on MBP. When a jurisdiction thinks it's dealing with a perpetrator, they recruit Lasher as expert witness. In a typical week, she fields dozens of e-mails and calls, and during any given month she's flying around the country, testifying in court.

"Because they rarely admit to their acts and deny any wrongdoing, they are generally incurable," Lasher says. "So I've never recommended reunification in a genuine MBP case."

Whether due to extreme stigma or the rarity of the phenomenon, few self-identified victims ever speak out. "They are very vulnerable to public attention since this kind of publicity is typical of the kind of victimization they experienced," explains Harvard psychologist Catherine Ayoub.

Those coming forward, moreover, don't necessarily have tales as neat or paradigmatic as the classic definition of the syndrome might suggest. Bree, now 29, says her mother withheld crucial antibiotics as an infant, causing her to remain perpetually sick. Her health stabilized during childhood, but then, at age 12, it all

changed when her mother learned Bree had been named after her father's childhood crush.

From that point on, Bree says, she could taste the sickly sweet flavor of purple gum—it turned out to be the emetic ipecac—in food her mother prepared for her. After such meals Bree suffered uncontrollable vomiting and dehydration, eventually becoming so impaired that she often missed school and was confined to a wheelchair. "It was always worse in March, around mom's birthday," Bree recalls.

She was almost 18 when doctors found toxic levels of the anti-seizure medicine Depakote in her blood, despite their explicit orders to stop that treatment. The police were called and Bree was carted off to a foster home. "At first I didn't believe it, and I wanted to get back to Mom." But a new, loving family and years of therapy have helped her recover and convinced her of the abuse. "I was never sick after I left Mom," Bree says. Bree's mother appeared to be punishing her for the perceived transgressions of her father, but she also basked in the attention that a sick child conferred on her, Bree says today.

Another survivor, Lauren—not her real name—is now 40. Her violent mother had long beaten her. Then she began giving ipecac and paregoric to Lauren and other children while baby-sitting, regularly causing them to throw up. "I knew what she was doing, and I was furious," says Lauren, "but she said she would kill me if I told." The medical abuse stopped a year later, when a pharmacist refused to refill the prescriptions. "Then the beatings increased," Lauren recalls. Now a clinical social worker, Lauren reflects: "My mother felt she had no family or support, though she

"I WAS NEVER SICK AFTER I LEFT MOM," SAYS ONE WOMAN WHO WAS ABUSED BY HER MOTHER, AND RECALLS THAT SHE WAS MOST ILL EVERY MARCH, HER MOTHER'S BIRTH MONTH.

did. No matter how much was done for her, it was never enough."

Lauren says that despite all her education and sophisticated understanding of abuse, she remained afraid to speak out until her mother died of a massive heart attack in 2002. "There is fear of not being believed and fear of retaliation by the abuser," she says. Both women now maintain limited contact with their families of origin.

FALSE ALLEGATIONS

DESPITE ALL THE THEORIES AND PROSECUTIONS—DESPITE reports of abuse by children now grown—Munchausen by proxy has never been embraced as a formal diagnosis by the American Psychiatric Association in its diagnostic bible, the DSM-IV. Not yet a proven entity, the syndrome is a theory waiting for research to validate it as real.

Even if Schreier's theories on motivation are eventually borne out in studies, the problem of false accusations will persist. In case after case, families with complex medical histories have been stripped of their children and left to fight for custody in court.

One such mother is Mannie Taimuty-Loomis, whose son, Jonah, had cerebral palsy and was mentally retarded and blind. He died of heart failure at age 3 in 2001. After his death, doctors suggested he'd suffered mitochondrial disease, in which the cell's energy factories malfunction, causing a wide array of ills. Moving on that hunch, they finally diagnosed the condition through a muscle biopsy performed on Jonah's older brother, Ezra, who, like their younger sister Symia, had been sick from birth.

Mannie and her husband, Ron, who was training for the ministry, founded the nonprofit Jonah & the Whale Foundation to

ease. They were skeptical of the diagnosis. When Terri came in to confirm it, she was labeled suspect as well. Mimi was released from the hospital, but doctors had called authorities. Terri was brainwashing Mimi, they charged, by convincing her she had Lyme disease. The phrase Munchausen by proxy was written into the medical record, and an investigation launched.

When a lawyer called to warn that Catawba County agents could be on their way right then, Mimi slipped out the back door. First she said good-bye to her beloved horse, then she went down the road. Terrified they would pull her Lyme treatment and lock her away for years, Mimi simply disappeared, contacting Terri just sporadically to let her know she was safe. In May 2007, having turned 16, Mimi found the only out available to her: She married her boyfriend, ending the dominion of the state. Mimi was declared emancipated, and the case was dropped in June.

"We had so many losses," Mimi says. She's particularly saddened by the death of her horse's foal. "She wouldn't have died if I'd been there," she reflects.

"Marriage at 16 is not what I wanted for her, but it was our only choice," says Terri, who's invited Mimi and her new husband to live as a family in her home. "We're trying to rebuild our lives, but moving past it is so hard. I know bad things

happen in life, but good God, do they have to traumatize people like this?"

MUNCHAUSEN MAY BE DREDGED UP TO SCAPEGOAT MOTHERS WHEN DOCTORS DON'T HAVE ANSWERS.

INSTEAD OF DIAGNOSING THE CHILD WITH A DISEASE, THEY DIAGNOSE THE PARENT WITH A CRIME.

help other parents of the chronically ill. They also brought Ezra and Symia to top medical experts, who agreed the children had mitochondrial disease and treated both aggressively. Despite that, they became so ill they too seemed headed toward certain death.

It was a resident at Pittsburgh's Mercy Hospital who blew the whistle in 2004. As the head of an organization for special-needs families, Mannie fit the typical MBP-parent profile, after all, and the resident didn't believe her children were truly sick. Child protective services took little Ezra and Symia, removing the intravenous lines that delivered their nutrients and drugs, stopping the treatment cold. Dramatically—in what could be interpreted as confirmation of MBP—the children (who *did* have mitochondrial disease) nonetheless began to improve. Yet it hadn't been Mannie who'd lobbied for all that medication, but some of the top doctors in the world.

"It's so ironic," says Mannie Taimuty-Loomis, whose trial took place on 15 separate days spread over nine months, a period during which she was separated from her kids. "Our children were the patients of 15 doctors, and not one stopped to think that it could be the treatment, not the disease they had, that was making them that sick." The court agreed, vindicating Mannie and Ron of any wrongdoing in 2005.

Also falsely accused was Terri Reiser, a North Carolina artist, whose 16-year-old daughter, Mimi, is diagnosed with Lyme disease and is under a specialist's care. Last year, Mimi was bullied by local teens who posted nude pictures online and falsely said they were photos of her. Frantic over the situation, she landed in the hospital, where she told psychiatrists about the Lyme dis-

THE PERFECT STORM

HERE IN THE U.S., AWARENESS OF MBP MAY BE RISING ALONG with antagonism between doctors and moms. "I have never known a false case not sparked by conflict between a mother and a doctor," New Hampshire psychologist Eric Mart states.

Schreier says powerless mothers are clamoring for intimacy with doctors. But he could be recalling an era past, when doctors were emotionally present and generous with their time. Indeed, the impersonal nature of modern medicine doesn't seem to support the Munchausen by proxy construct. Marching to the drumbeat of managed care, in fear of litigation, 21st century doctors may have little interest in schmoozing. They are often seen as distant by the very patients they serve.

Mothers, too, have changed. Best described by Judith Warner in her book *Perfect Madness: Motherhood in the Age of Anxiety*, post-millennium moms are intense, omnipresent, and highly involved. From finding the perfect nursery school to engineering marathon play dates, nothing escapes their attention and no detail is too small. Taught independence by their own feminist mothers, at home with their children by choice, these educated women aren't likely to defer to a doctor when a child stays sick. The more mothers learn, the more they access the Internet, and the more intense and independent they become, the more they will spar with doctors—and the more they'll be at risk of being labeled a Munchausen mom.

"If it were the man demanding help, wanting to know more and wanting to be involved, no one would think anything of it except, 'What a dad!'" says Mannie Taimuty-Loomis, now executive director of the Jonah & the Whale Foundation. "But when a mother displays the same characteristics she's deemed difficult to work with, overly interested, and very controlling."

"Diseases that can't be fixed can create enormous amounts of anxiety," adds Tracy Davenport, a University of Delaware expert on the social impact of illness. "Doctors want these patients out of their office, while the patients are filled with loneliness and despair—not because they want the doctor to love them, but because they want the disease to go away."

Pennsylvania psychiatrist Virginia Sherr has a special interest in Lyme disease, whose neurocognitive symptoms can seem bizarre and vague. She says she's seen false allegations time and again when a mother tries to get help for a child who's truly sick. "Modern medicine tends to trivialize women's seemingly offbeat concerns, and hurried physicians who seek easy panaceas drastically devalue mothers' opinions," she states. "Worldwide, there have been thousands of very sick children forcibly removed from mothers because these women have insisted, quite knowingly, that their children are ill."

"We are seeing a conflict between doctors and patients that didn't exist before," says Davenport. "Mothers are increasingly demanding consumers. They are texting friends by BlackBerry and getting information in minutes that trumps what their doctors advise. Rather than idolize their doctors, they are apt to antagonize them, leading to more misunderstanding and more charges of MBP in years ahead."

Mannie Taimuty-Loomis, meanwhile, thinks the next wave of allegations could come from the rising tide of autism diagnoses. "I see all the red flags," she states. "There is no definitive diagnostic tool, it is a spectrum disorder that has a wide confusing range, and parents are being hit like ping-pong balls with differing opinions, treatments, and diagnostic titles. This is a toxic mixture for accusations of MBP."

IMAGINARY MONSTERS

WHEN CHILDREN SUFFER COMPLEX, OR CONTROVERSIAL, or confusing illnesses, when symptoms are amorphous or vague, parents can be accused. The situation has been compared by SUNY Stony Brook philosophers David B. Allison and Mark S. Roberts, authors of *Disordered Mother or Disordered Diagnosis?*, to the witch trials, in which thousands were killed around the world. As with MBP, the women were perceived as abrasive and paid a heavy price.

The intellectual dilemma here, says Kirk Witherspoon, an Illinois psychologist studying the issue, is that two unrelated elements have been mixed. One of them is motive, which is a cause. The other is abuse, which is a result. There's no proof that the theorized motive—a need for attention—

explains the abuse routinely labeled MBP. But that doesn't stop some doctors from "dredging up motive to scapegoat mothers when they don't have answers," says Witherspoon. "Instead of diagnosing the child with a disease, they diagnose the parent with a crime. When mothers challenge their authority, doctors call it a pathology, one that's so broad it fits everyone. For example, if the mother is too friendly, a sign of Munchausen. If the mother is angry, a sign of Munchausen. There's no differential diagnosis. It's preposterous. It doesn't make logical sense."

Feldman attributes the confusion, in part, to invalid profiling. "There is no profile," he says. "There has to be proof."

But there, too, problems abound. Subject to misinterpretation, tools like covert taping (used to entrap Kelly Savage) and family separation (the evidence against the Taimuty-Loomis family) can lead to false allegations. Children who suffer from acid reflux are a prime example. They are often treated with Reglan, a drug that can cause seizures and a full range of unusual side effects. Mothers are blamed for the symptoms, and then separated from their children. The treatment is stopped, and the children get well, apparently confirming MBP. And since many conditions improve on their own over time, the separation test is an imperfect investigative tool.

In light of all this, even doctors convinced of MBP's reality are pulling back. Feldman insists the syndrome exists, but says "we've gone too far. Those of us on the front lines must take ownership of the problem and admit we've been overzealous. Innocent mothers have been accused." Feldman is especially trou-

"IF THE MOTHER IS TOO FRIENDLY, IT'S A SIGN OF MUNCHAUSEN. IF THE MOTHER IS ANGRY, IT'S A SIGN OF MUNCHAUSEN. THERE'S NO DIFFERENTIAL DIAGNOSIS."

bled because when vindictive doctors make false reports, they're protected by the law and consequences are nil.

"We have created a monster in our imagination that we project onto certain mothers," Pankratz says. "Some of these mothers have problems in the medical management of their children and need clinical help, but the exotic label has entangled them in a destructive web, seemingly without escape."

Eric Mart points to psychiatry as a field rife with discredited theories—for instance the idea that "refrigerator mothers" create autistic kids. When studies are done, such concepts are relegated to the dustbin of science, and MBP stands poised to end there, too, he states. "I'm not saying the abuse doesn't happen," Mart emphasizes. "I'm just saying the theory behind the syndrome doesn't hold up."

"Why call it Munchausen," asks Kirk Witherspoon, "when you can just call it abuse or murder." ■