

A BOY IN A MAN'S BODY

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With a mischievous sparkle in his eye, the young man hops off the kitchen stool and dashes into the living room. He pounds his fingers on the keys of the piano, exploding into peals of hilarious laughter at the racket made by notes crashing together.

He struts into the family room, collapsing on the couch next to his mom. He slumps in his seat, fidgeting.

Finally retreating to the quiet safety of his bedroom, the man snuggles into bed, wraps his arms around his favorite, worn teddy bear, and begins sucking his thumb.

[Photo: When not on a subduing medication, 20-year-old John Kellerman easily bursts into laughter.]

This is the life of 20-year-old John Kellerman, without medication.

John has fetal alcohol syndrome. His birth mother was an alcoholic and drank heavily throughout her pregnancy. The day John was born, his mother showed up at a Denver hospital drunk. When her water broke, the smell of alcohol permeated the delivery room.

"He was pickled in alcohol," said the woman who would later adopt him.

John, who was premature and weighed 2 1/2 pounds, was found to have FAS at birth. The alcohol caused heart defects, brain damage and vision problems. When his biological mother was told he had problems, she wanted nothing to do with him. But by some miracle, this fragile, helpless, brain-damaged baby happened into the home and heart of a true angel. He was taken home from the hospital and later adopted by Theresa Kellerman, a foster mom who, with her husband, Bob, had cared for children with special needs.

The young woman didn't know how much John and his syndrome would change her life. Kellerman, now 50, dedicates her days to giving John every opportunity to succeed, as well as helping other families understand and cope with the devastation brought on by prenatal alcohol exposure. Kellerman, the mother of three, has raised John as a single mom since she and her husband divorced in 1984. She appreciates John for the young man that he is.

John has permanent brain damage. His IQ is 68, making him borderline retarded. Academically, he is at a fourth-grade level. Emotionally, he is 6 or 7. This is about as advanced as John will get. "His brain has reached its capacity," Kellerman said. "When he's not on his medication, it's like he's drunk. He will live the rest of his life like this."

It's rare that John misses taking Ritalin. The medication helps him focus and keeps his emotions in control. "I fought and fought against him being put on medication," Kellerman said. "It was a drug that got him into trouble in the first place, and I wanted to keep him drug-free." But John's emotions became uncontrollable, and he was careening through life, riding on wild waves of hyperactivity. Kellerman finally agreed to put her son on Ritalin when he was 10. "It was like he sobered up. When it wears off, it's like watching him get drunk." The first hour in the day, when his medication hasn't kicked in, can be the toughest, Kellerman said. "He can be immature and inconsiderate. He can say things he doesn't mean. I have to be careful not to take it personally. "But the rest of the day, he's a pretty neat kid."

Kellerman's days are filled with John and his FAS. "I don't do a whole lot else other than be his mom and his conscience and his judgment," Kellerman said. "I'm here for him." John attends Howenstine Special Education School, where he learns job training and personal living skills. He can stay in school until he's 22.

John's memory is poor, and he has a hard time mastering basic skills. "It took years and years and years for him to learn to tie his shoes," Kellerman said. "He has a really hard time with money. You can ask him four times how many quarters in a dollar, and you'll get a different answer every time. We'll work on it for days, and I'll think he has it, and then you'll ask again and he'll tell you 50 or 10 or three. He just doesn't remember."

[Photo: Theresa Kellerman shaves the face of her son John, who lacks the concentration to shave himself.]

Kellerman worries about what will happen to John after he graduates. She worries even more about what will happen to John when she's gone. "I look at John, and I think, 'He wants to be independent and he can't be. 'He knows if his birth mother didn't drink, he wouldn't have these problems. It's very depressing. When I think about it or talk about it, it causes a lot of emotional pain. I fear for his future. The services are not in place for him to be happy and healthy, and he's just one kid. What about all the others? It's simply overwhelming."



When Kellerman adopted "Johnny" 20 years ago, information about FAS was just coming out. But Kellerman didn't need scientific studies to know the baby was a handful. Johnny could handle no stimulation. He cried pitifully and slept fitfully. "He cried and cried and cried, and nothing soothed him," Kellerman recalled. Johnny was overwhelmed by sound and light and couldn't concentrate on drinking the baby formula Kellerman offered. She desperately wanted to cuddle her baby boy and offer the love he was missing from his birth mother. But John didn't want to be held. The more Kellerman tried to sooth him, the more upset he grew. So Kellerman learned to love Johnny from a distance.

As a toddler, Johnny was charming and loving. It was then that Kellerman first told him about FAS. "He'd sit on my lap as a baby, and I'd talk about his adoption and his syndrome," she said. "There's been nothing hidden."

As John grew, so did his problems. His hyperactivity became more severe. He grew angry at his birth mother at around 10. "I can remember him sitting at the kitchen counter, saying, 'Do you mean if my birth mother didn't drink, I wouldn't have these problems?'" Kellerman recalled. "I said, 'That's right,' and he got so angry."

Another problem that plagues John is the physical contact he craves. He has always loved to give hugs. As he grew older, the hugs became more sexual, and Kellerman worries John's hugs will get him in serious trouble. Her biggest fear is that he could be arrested for inappropriate sexual behavior. "We have to have a concrete rule: No hugs," Kellerman said. "He can have as many hugs from me as he wants. He has plenty of people providing affection."

Earlier this month, John started taking Paxil, an antidepressant Kellerman hopes will control his sexual urges. John knows he's not supposed to hug women he doesn't know. But when Kellerman isn't looking, he tries to make physical contact. John's hugs have gotten him in trouble at school and in the community. Afraid that he would be arrested, Kellerman drummed into John's head that he could be locked up if he weren't careful. "He became so afraid of that, he told me maybe it would be better to be dead than be in jail," Kellerman said.

Kellerman continually reassures John that she'll be his conscience. "I told him he'll never be in jail, as long as I am with him," Kellerman said. "I'll provide him with 24-hour supervision if that's what it takes." For John to succeed, he must live and work in a highly structured world, Kellerman said.

She found herself nagging John about what he needed to do. So for the past couple of years, Kellerman has kept a detailed schedule on the kitchen wall. "He's learning to be responsible for himself. He asks me, 'Mom, what am I supposed to be doing?' And I'll say, 'Check your chart.'"

It all starts with his alarm going off at 6:30. Shower 6:40. Shampoo 6:50. Put on deodorant at 7, take Ritalin and make the bed. Feed the dog at 7:15, eat cereal, brush teeth and get out the door for the school bus. And so on and so on, throughout the day, all day, every day. "His neurological process is so messed up, he'll never be able to remember all of this on his own." Kellerman said, looking at the chart. "We've got making the bed in the morning down pat. But he still can't remember to use his deodorant."

Parenting John, as difficult as it is, is the easy part, Kellerman says. "The hardest part is dealing with teachers and professionals," she said. "You have to really know all about FAS and what it is to make a positive impact." Kellerman frequently meets with John's teachers, counselors and other professionals. She's in his corner every minute.



[Theresa Kellerman and her son John share a quiet moment.]

The young man longs to be independent. "I want to live on my own, away from my mom, with a roommate," John said, stretching his 4-foot-10-inch frame on the family room couch, his mom at his side. Kellerman is all in favor of this, but she knows it won't come easily. "I'm going to do what I can to help him reach that goal," she said. "He has fears about what's going to happen to him in the future. Maybe we can use this house for John and two or three other people who wish to live here with a live-in person. "My main goal is that John will always have some supervision, someone watching out for him. I've set up a trust fund to pay someone to be a buddy, to come in and make sure he's had a shower or whatever. I may have to get a job to subsidize his independence."

On medication, John seems competent and in control. But in reality, his level of functioning is low. Around the house, John does his laundry, helps sort recyclables and does a few other chores. His only minutes of freedom come when he takes his dog, Scarlett O'Hairy, out for a walk. "That's the only thing he does by himself, and it's not without fear on my part," Kellerman said. "The dog is actually taking care of him."

John's favorite pastime is playing the drums. Best of all are the times when he jams with his younger brother, Chris, 16, who composes music and plays electric guitar and piano. "Some of my friends ask how I can stand all that noise," Kellerman said. "I think it's great. It's something positive. It increases his self-esteem."

John dreams of being a rock 'n' roll star. "He fantasizes about friendships and life and being normal," Kellerman said. "But in reality, he doesn't have any friends. No one calls him and says, 'Let's go do something.'"

John rarely thinks about his birth mother anymore. Kellerman believes the woman, who was 36 when John was born, probably died a couple years after his birth. His father's identity is unknown. "I have no clue who my father is," he said. "Maybe the pregnancy was an accident. Maybe they were just playing around. You do funny things when you're drunk, like get pregnant."

Kellerman frequently talks to John about the dangers of drinking. "I think if someone handed me a drink, I would throw it against the wall," he said. And she talks to him about the importance of using birth control. But he dreams of having a family. "Don't you think I'd be a great dad, Mom?" John asks. "You'd have to take care of someone else. You have a hard time taking care of yourself," Kellerman responds. "Yeah, but it would be neat to have a son to carry on the tradition," John replies. "Having a son means you can have man-to-man talks." Kellerman smiles at John. But at the edge of the smile is worry. The two have talked about the fact that John should never have children, Kellerman said. "We've talked a lot about sterilization," Kellerman said. When he's on his medication, "he knows there's no way he could take care of a child. So he thinks maybe it's best to have a vasectomy. But we're going to wait a while before making a decision, to make sure it's the best thing."

Kellerman knows her son's limitations. "John will never be able to totally be on his own. He will always need help the rest of his life. He will always be living under a permanent hangover."

For more information on Fetal Alcohol Syndrome and related disorders, visit the FAS Community Resource Center: www.come-over.to/FASCRC