



# A Different Kind of Normal

**The Challenges and Triumphs  
of Jimmy Foard and His Family**

BY CHARLOTTE MERYMAN

The moment she reads “Dress as a Superhero” on the invitation, Michelle Foard is sure her 4-year-old son, Jimmy, is headed for yet another birthday party disaster. “They’ll have,” Michelle guesses, “all the things he doesn’t like.” Like the dreaded bounce house. With his low muscle tone and poor balance, Jimmy hates being jostled on such a billowy surface. Or an arts and crafts table. It’s too frustrating; Jimmy’s fingers never seem to do what he wants them to do. The way things usually unfold, when no activities click for him, is that Jimmy retreats into himself. This pains Michelle and her husband, Jim, for it defeats the purpose of braving the party in the first place: connecting with other kids.

Yet this doesn’t stop Michelle from RSVPing a firm yes. They will go, but with one concession: She’ll intentionally arrive late in hopes of minimizing his time there. When the day comes, she keeps Jimmy quiet at home all morning to conserve both their energies and fights off a sense of quiet doom. At 3:00, she slips a Superman T-shirt over her son’s head, waves good-bye



to Jim and their almost-2-year-old, Maddie, and lifts him into his car seat. And they set off.

Michelle is determined that Jimmy go to as many parties as he can now. “Because I figure at some point,” she says, “the invitations will stop.”

That knowledge, it must be said, is one of the most piercing parts of parenting a child with special needs. Differences may not matter much to preschoolers, but as kids grow up and friendships cement, the child who can’t easily play with others becomes the child who gets left out. Jimmy has been asked to a few playdates, but already Michelle has noted that unless the mom is a friend of hers, “there’s no repeat.”

Jimmy is tall for his age, with milky skin, fine brown hair, and almond-shaped blue eyes that hint at his Irish, German, and Filipino heritage. He’s almost a carbon copy of his affable father, Jim Jr., a financial advisor—Jimmy’s family calls him Jim’s “mini-me.” He’s a gentle child. He has a great laugh.

Jimmy also has Alfi’s syndrome, a rare disorder (the University of Chicago, a leader in the research, has registered about 200 cases) in which part of the ninth chromosome is missing. Also known as 9p minus, deletion 9p syndrome, or monosomy 9p (“monosomy” means one chromosome short of a

fully matched set), the condition is colored by physical and mental delays. The challenges vary from child to child, due to which portion of the chromosome is affected.

Jimmy has been fairly lucky on the physical front, although he does wear ankle braces to correct his badly turned-down feet. It’s his low muscle tone that poses the most problems—especially when it comes to his speech. At age 4, he still cannot form any words, much less whole sentences. He manages only a few basic sounds, such as “guh” and “ma,” which can mean many different things depending on the context.

His difficulties are magnified by the fact that he also has autism spectrum disorder, a brain disorder that interferes with his ability to learn, communicate, and form relationships. It’s still unclear whether the autism is tied to Alfi’s syndrome. Jimmy has always been affectionate with close family members. But when it comes to kids, “he could care less about being part of the group,” says Michelle.

It’s a quality that hits Michelle very hard. Trim and put-together—she was a golf pro before she became a mom—she favors pastel shirts, khakis, and pearl stud earrings. But her conventional attire

**SIBLING REVELRY**  
Maddie, almost 2, is Jimmy’s “greatest cheerleader,” says Michelle. Each morning, she gets two sippy cups and gives one to her brother. And she loves to chime in “Good job, Bubba!” whenever he gets praised.



belies a lifelong sense of being an outsider. Born in the Philippines to an American serviceman and a Filipino nightclub singer, she moved with her family to Texas when she was 7. From then on, she says, she's always felt different, "being a child who's not completely white, not completely Asian." By college she was so self-conscious, "I used to put makeup on for an hour and a half before I left my dorm room."

princesses dashing about are preschoolers from Jimmy's class at Longmeadow's Blueberry Hill School. The kids are climbing on and off swings, hopping in and out of ride-on toys, and jumping on a small trampoline. Well, at least there's no bounce house, Michelle notes with relief.

She hands their gift to the birthday mom and focuses on coaxing Jimmy to say, sign, or wave hello: a first step in drawing him out. Michelle casts



Days after he was born (left), Jimmy's parents found he had Alfi's syndrome, a rare chromosomal disorder; a diagnosis of autism would come later. Jimmy wore a helmet from 6 to 11 months to remold his misshapen head (center). At 11 months, Jimmy had surgery to separate the fused plates of his skull; you can see the telltale ridge on his forehead (right).

Living now in Jim's affluent, mostly white hometown of Longmeadow, MA, hasn't helped. "I'm just some goofball from Texas!" she laughs. "I get nervous around these successful people and their wives." Raising a child with special needs has made her feel even more set apart. But it's also transformed her. "She's been forced to represent Jimmy at all turns: at school, at the doctor's office, in play groups," says Jim. She's blossomed from a timid, reserved woman into a bold advocate "who will do whatever her son needs."

"I can take anything," Michelle concurs. "I can take Jimmy being slow; I can take him not knowing anything academically. I just can't take his having behavior issues, because if he can't interact with society, what kind of life could I hope for him?"

## Braving the Party

The superhero party is at full tilt when Michelle and Jimmy get there. Most of the heroes and

about for a way to join the party and quickly spies the swing set. She guides Superman down the slide, where two boys in Spider-Man and Batman costumes are dancing around a big red plastic wagon. Jimmy peers into the wagon, and Michelle seizes the moment. "How about if Jimmy sits in the wagon and you guys pull him?" she suggests brightly.

Success: She sets Jimmy inside, and the superheroes excitedly cart him across the lawn. Jimmy grins as he bounces along. But the victory is short-lived. The boys soon dart back to the swing set, leaving Jimmy, who can't manage climbing out of the wagon, adrift. He gazes about in puzzled frustration until his mother, now chatting with another mom, spies her stranded son and liberates him.

For Michelle, whose long days are spent driving Jimmy to and from his school and his occupational, physical, and speech therapy sessions—not to mention chasing after Maddie, who'd scamper to the rooftop if you let her—catching up with other adults feels great. Yes, the party is rife with minefields, but

it's also a prime chance for Michelle to connect. Over the next hour and a half, with one eye (and often one hand) on Jimmy, she steals time to talk.

She visits most with Chris Panetti, mom of Jimmy's classmate Robert (aka Spider-Man). Robert struggles with speech and sensory processing problems. Michelle finds she feels most at home with other parents of kids with special needs; Chris gets the big picture. It's a comfort.

enough. After several tries, he finally squeezes in, and a minute later emerges on the other side, his face a study in concentration.

Now they're at the swing set, which has a ladder up one side: as bad as scaling the Matterhorn in Jimmy's book. He still seems engaged, so Michelle forges on, heaving his braced legs up one rung at a time. At the top, he's supposed to head down the slide, grabbing a teddy bear from a girl swinging on



Jim spots Jimmy on the slide, much to Jimmy's obvious delight (left). The Foards worked ceaselessly to help Jimmy walk, a milestone he reached just before age 3 (center). For the first time ever, father and son walk down the driveway together to get the paper (right).

“That,” says Jim, “was one of the best days of my life.”

The birthday mom has an announcement: Time for the obstacle course! More like the nightmare course, thinks Michelle. Typically, Jimmy either cries or walks away from setups like this. It's not that he's fragile. Jimmy loves roughhousing on land and in water with his dad. It's just that he's not interested. Michelle warily looks over the homespun arrangement of lumber and toys—it's actually pretty tame—and resolves to give it her best shot.

Michelle shepherds Jimmy to the first obstacle, a balance beam of boards laid end to end on the grass. Still chatting with Chris, she guides him from start to finish. Surprisingly, he follows along, staying mostly on the wood. Michelle lifts him onto a scooter and pushes him to the trampoline, where she holds his torso and bounces him up and down a bit. He's three for three so far and still no tears.

Next up? Crawling through a yellow fabric kids' tunnel. Michelle shows Jimmy how to bend down to ease inside, but he has a hard time squatting low

a swing next to him. Michelle tries repeatedly to explain the trick, but it isn't clicking. Finally, Michelle grabs the bear, and Jimmy manages to drop it in the wagon below. And the course is over.

Michelle is thrilled. It may not seem like much to most kids, but for Jimmy it's a real triumph, and she heaps on the praise. The truth is, raising Jimmy has forced the Foards to constantly readjust their hopes and expectations. It's a process that began, without warning, soon after his birth.

## In the Beginning

James Frederick Foard III arrived full-term just before midnight on March 14, 2001—Michelle's 29th birthday—after an uneventful pregnancy. The first hint of trouble came early the next morning, when a pediatrician stopped in to say there were a few things that concerned her about baby Jimmy: He had widely spaced nipples, which could spell heart problems. His high, sloping forehead, low-set





**IN HIS ELEMENT**  
 “We love him,” Jim says of Jimmy, who feels most at home in the water. “He’s perfect. But in the beginning, I was angry that my son had to go through life with deficiencies he shouldn’t have to go through. I don’t know if I was angry at God or who I was angry at. I was just angry.”

## A Good Read

*My Friend Isabelle*  
 by Eliza Woloson  
 (Woodbine House).  
 This is the kindly story of two friends, one with Down syndrome, one without. A great way to introduce children to the world of friendship and disabilities.

*We Can Do It!*  
 by Laura Dwight  
 (Star Bright Books).  
 Spirited children with various disabilities (such as blindness, cerebral palsy, and spina bifida) show all the things they can do.

ears, slanted eyes, and big hands and feet could indicate a genetic abnormality.

It took five days of exams and blood tests—five terrifying days—and then the preliminary results came back. There was a problem with the ninth chromosome. Unraveled by panic and confusion, Jim and Michelle were soon put in touch with Beverly Udell, then president of a Web site run by parents of children with Alfi’s syndrome ([www.9pminus.org](http://www.9pminus.org)). “She gave us a list of all the medical conditions he could have, and then we asked questions,” Michelle recalls. “We wanted to know what he would be able to become when he grew up. We asked, ‘Will he play sports?’ and she said probably only Special Olympics. We asked, ‘Do these kids ever go to college?’ and she said no. We asked if any of them have families, and she said they don’t have the mental capacity to hold a job or take care of a family.” It was all too much.

“How can you say that to someone with a child who’s five days old?” asks Jim angrily. “I didn’t like being told that our child is going to follow a certain road, do certain things, not be able to do certain things. He was being put into a

category, and his own personal identity was being taken out of the mix. *He was a baby boy, not a 9p-minus baby boy.*”

Udell is surprised the Foards came away with that feeling, since it’s exactly the opposite of what she tries to convey. But she understands that the early days of diagnosis can be overwhelming. “The hardest part is that you’re talking to a parent who’s just had the shock of their lives,” says Udell. “Parents come into the conversation with me having different hopes and dreams, and sometimes I’m the messenger. These parents may not be ready to hear what I have to tell them.”

Michelle is philosophical now: “Maybe,” she says, “we were asking the wrong questions.”

## The Right Questions

In the years since, they’ve learned to focus on the right questions, or at least the timelier ones. Back at the party, for example, Michelle wonders: Will Jimmy get through the birthday cake ritual? He often cries when the candles are blown out. Yet as the kids crowd the two cakes, decorated like Powerpuff Girls, Jimmy claps along as everyone

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sings and doesn't cry. Afterward, he draws near to the enticing cakes. But a little girl stops him with a commanding, "You can't touch it, Jimmy! Don't touch it!" It's one of the only times all day another child has spoken to him.

As the girl of honor begins opening her gifts, it grows clear that, Superman or not, Jimmy has reached his limit. He wanders to the small trampoline, lies on his back, and gazes into the sky. And the tears, held back for so long, pour down. Michelle soothes him as he sobs in her arms.

The princesses are gathered around the gifts, oohing and aahing as each is opened. Michelle carries Jimmy over to fetch his present from the table and silently adds it to the line in front of the birthday child. She's not about to ask for special favors—like having his gift bumped ahead—and tries to distract him for the time remaining.


Jimmy makes for the gate, but she stops him. "Let's just wait until she opens your present," she coaxes. "You can do it." Pulling him close, she delivers a series of long, loud kisses to his temple, eliciting louder and louder giggles until finally he is laughing hysterically. And then they are saved.



**Charlotte Meryman has written widely about those with special needs. She's at work on a memoir about life with her brother, who is developmentally delayed.**

"Jimmy, thank you!" the birthday mom at last exclaims as her daughter rips open his gift. "Good job, Jimmy!" Michelle says, hugging him. "You did it! You kept it together!" Later, Michelle will say, with a big smile, that this "was the best party he's ever had." But right now, her relief is matched only by her exhaustion. "Hang in there," Chris Panetti says as they ready to leave. "You're doing a great job."

And she is. Michelle and Jim have risen to the profound occasion of raising their son. "We want to give Jimmy every possible chance to excel," says Jim. "We love him. He's perfect. But he's going to have some very serious issues we're going to have to deal with for the rest of his life." It's a future they've learned to make peace with. "It's life now," explains Jim. "It's part of everything we do." Michelle searches for another way to explain what it's like to be Jimmy's parents. Ultimately, you learn to embrace "a different kind of perfect," she says, and "a different kind of normal."

*Next in the series: Jimmy begins to find his voice, through speech therapy and a new talking device, and the Foards confirm what they expected: There's a smart little boy in there.* 

### Resources and Credits

**TIME WILL TELL** pg. 95: Bead kits by Bead Bazaar, \$23, [backtobasicstoys.com](http://backtobasicstoys.com). For this article, author Lynne Bertrand relied on the research of the Gesell Institute of Human Development; the studies of how the mind "travels" in time by William Friedman, professor of psychology at Oberlin College; the works of Anthony Aveni, professor of astronomy and anthropology at Colgate University; and the practical experience of Rita Harris, a veteran preschool teacher at

the Smith College Center for Early Childhood Education in Northampton, MA.

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