

A glass of Florida sunshine

BY BRUCE DEACHMAN, THE OTTAWA CITIZEN APRIL 30, 2012



There were numerous times during the day when Jake Booth, 10, simply couldn't contain his excitement.

Photograph by: Bruce Deachman

OTTAWA — Jake Booth was born with cerebral palsy and suffers scoliosis so severe that he's endured 14 operations over his 10 years. The unlucky 13th procedure, done just over a year ago to insert rods in his back to lessen the possible damage from his deteriorating spine, didn't have the intended outcome, and Jake now uses a walker to get around — or a wheelchair for longer outings, such as when he goes to the mall.

Yet despite conditions that many might find wholly dispiriting, the Kemptville boy insists he's not disabled, and that there's no such thing as inaccessibility; he just has to find different ways to do things. The hurdle he cleared last Tuesday, for example, was simply another example of getting on with the life he wants to live between operations.

So as the Boeing 737's wheels lifted off the Ottawa airport runway shortly after 6 a.m. and the sun finally poked over the eastern horizon, the cheer that Jake and 77 other kids aboard the plane spontaneously let out had little, if anything, to do with the cerebral palsy, muscular dystrophy, sickle-cell disease, spastic diplegia, brain tumours, progressive familial intrahepatic cholestasis, lupus, Takayasu's arteritis, juvenile arthritis, encopresis, transplants and amputations that beset the CanJet passenger manifest like a medical textbook run amok. Rather, the applause that burst from these six- to 17-year-olds originated in the parts of their brains that told them this one simple fact: today, they were going to Disney World.

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The one-day trip, or “DreamLift,” was organized by the Sunshine Foundation of Canada, a charity founded in 1987 by a London, Ont. police officer whose son died of muscular dystrophy. The organization’s mandate is to fulfil dreams for children with special needs — either severe physical disabilities or life-threatening illnesses — and over its 25-year history, CEO Nancy Sutherland estimates the group has helped some 7,000 kids visit Walt Disney World or its sister park on the west coast, Disneyland. They’ve organized DreamLifts from cities all across Canada, Sutherland says, from Halifax to Vancouver.

Additionally, Sunshine organizes individual trips for kids whose illnesses are too severe and needs too great to include them in group trips. In those cases, the trips can be to other destinations, may include family members and usually last longer than a day.

With no government or United Way funding, however, the trips are expensive to stage, and the foundation relies on corporations, community groups and third-party fundraisers to find the \$160,000 that each costs. Last week’s trip from Ottawa, the 50th in the organization’s history and the third from the capital, was backed jointly by the Ontario Automotive Recyclers Association and the Automotive Recyclers of Canada, allowing nearly 80 children and as many or more volunteers — most from the ranks of CHEO, the Ottawa Children’s Treatment Centre and the RCMP — to make the trip.

The source of all this benevolence, however, was beyond Jake’s concern. He’d wanted to visit Disney World for years, in particular the Haunted Mansion, which fit in nicely, he believed, with his fascination with zombie movies.

And despite the 3 a.m. check-in at the airport, or more likely because of his excitement, he’d stayed up late the night before — ’til 9 p.m. — reading Thomas the Tank Engine and practising his break dancing so he can make a good impression if and when he appears on Canada’s Got Talent and/or Ellen DeGeneres’s talk show, Ellen.

The ebullience in the plane, even at six in the morning, was electric. The cheers and applause started as the narrow-body jet was pushed away from the apron and onto the runway. Passengers clapped as the takeoff began, reaching a crescendo as the plane became airborne. The further praise that followed the flight attendants’ emergency procedures demonstration abated enough for breakfast and an inflight screening of Happy Feet 2 (“It’s actually better than the original Happy Feet,” promised Braydon Barker, whose cardiac difficulties appeared mostly unchanged by the fact he turned 16 at almost the precise moment the group was to arrive at Disney.) Even the pilot’s announcement, shortly after eight o’clock, that passengers could look out the plane window and see Charleston, South Carolina, some 38,000 feet below, drew cheers.

The 9 a.m. touchdown in Orlando, where even more volunteers — three dozen people from the Orange County Sheriff’s Office, the U.S. Drug Enforcement Agency and the Federal Air Marshall Service — joined the party, called for yet more cheering.

Buses took the kids and their helpers the rest of the way to the theme park, where signs large and small urged everyone to “Let the Memories Begin.”

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“I’m not afraid,” he repeated, “I’m not afraid.”

Disney World’s Haunted Mansion is perfectly suited to both Jake’s penchant and his tolerance for horror. When holographic ghosts appear, he nervously but excitedly shouted, “Dude! Take a picture! They’re real ghosts! They’re taking over!” And when he finally emerged: “Oh, my god, that was scary! They’re real!”

But after two more trips through the attraction, he easily denied he was ever frightened. “When I said that was scary?” he scoffed. “No, dude, that was for you, not for me.”

He liked the next ride, Pirates of the Caribbean, even more, claiming in the same breath that it was faster and scarier, but that he wasn’t scared. The race cars at Tomorrowland Speedway were faster yet, and deserving of a second run-through, as was the colourful, neon, black-lit Buzz Lightyear ride and the science-lab drama found in Stitch’s Great Escape. “There was a real teleporter!” he blurted. “It teleported people! And these claws came down and tried to get me, and I got wet. You have to try it, dude, you’ll pee your pants!”

With Fastpass tickets allowing the kids on this trip to bypass long queues and almost instantaneously access rides and shows, it’s easy to understand why the Sunshine Foundation has chosen one of Walt Disney’s two North American theme parks for all but two of its 50 DreamLifts (In 1995 and 1997, kids from Thunder Bay and Winnipeg, respectively, visited the West Edmonton Mall).

“Disney is really great at levelling the playing field for kids with disabilities,” explains Sutherland. “It’s fully accessible and the staff are extremely well-trained in dealing with kids with special needs.

“So kids can just be kids. They’re not kids with a disability there. Disney is the happiest place on earth — every time you turn a corner, there’s some happy song playing or there’s a smiling character.

“It really is the best place you could go for a day and just forget about whatever is troubling you.”

And say what you might about the uber-controlling and -marketing park that some Orlandroids disdainfully refer to as The Rat, the folks at Disney really do know how to hold on to a 10-year-old’s imagination, like a 30,000-acre arcade vented with serotonin and dopamine.

“This has to be real,” said Jake after emerging from the Peter Pan’s Flight ride. “How are we flying?”

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After a dozen or 15 rides, two meals, three bathroom breaks, one Main Street parade and an exit through the gift shop, it was time to leave the Magic Kingdom. Many kids were fast asleep by the time the buses reached the Orlando airport tarmac to load the plane for the 9 p.m. flight back to Ottawa. Volunteers administered medication to the kids who needed it, and the flight crew hurriedly distributed dinners of macaroni and cheese or chicken fingers. Bedtime stories were read to little ones, while those with greater stamina watched Alvin and the Chipmunks 3:

Chipwrecked. Jake held tight to the little metal Disney airplane he bought, directing it through loops, barrel rolls and dives above seat 9E.

And as the 737's tires lifted off the Florida runway for the three-hour journey home and the sun tucked itself in beyond the western horizon, there were no accompanying cheers or applause. Just the quietness of new memories settling in.

EPILOGUE

Jake remained awake for the entire flight home. At 11 p.m., he said he was practising his teleportation, and had just, in fact, been to the mall and back. "You can do it, too, dude," he said. "Just close your eyes."

He cleared customs and was greeted by his mother, Clare Skinner, at 12:25 a.m. She recalls the drive home to Kemptville as 20 minutes of excited and indecipherable babble followed by complete silence as he finally fell asleep in the car.

"To actually get away for a day and do this was totally beyond his wildest dreams," she said. "Totally. Nothing will compare to this, and he's been talking about it for weeks, to anyone who will listen: 'Dude, did you know I'm going to Florida? Yeah, just for the day.' Just non-stop.

"He's so thrilled to be doing anything that a regular child can do; something this amazing, he won't get over it."