

“My main focus now is to create more adaptive, accessible, universal, and barrier-free designs. And there’s a very, very, very small minority of the architectural world that addresses that.”

Jason

Born April 1985 | Columbia, MD

Living with DMD

Jason and Adele were tired from their day of travel and arrived at the Berlin central train station late in the evening, ready to get some rest. The mother-son duo had been in Prague for nearly two weeks, where Jason was studying sustainable architecture, with his classmates from the University of Maryland’s School of Architecture, Planning, and Preservation. “Our class was combined with a bunch of students from Prague,” remembers Jason. “We learned about designing buildings that were more efficient—that use less fossil fuels.” Jason was exhausted from the long train ride, and needed to find a bathroom before taking a cab with Adele to their hotel.

The attendant led them over to the “accessible toilet.” Jason rarely held high expectations about such devices, especially in public train stations. He was used to struggling to get on and off the toilet and back into his power wheelchair. Even in bathrooms with multiple grab-bars, his muscles were often too weak to lift himself onto a normal toilet. Jason was born with Duchenne muscular dystrophy (DMD), a neurodegenerative muscular condition that irreversibly weakens one’s muscle strength over time.

However, as a wheelchair user, Prague was a welcome surprise, especially the public transit system. "About 90% of the public transportation was accessible," says Adele. The two were delighted to navigate the medieval city with relative ease. A similar surprise was in store at the train station in Berlin. As soon as the attendant unlocked the door and swung it open, Jason and Adele were taken aback by what lay inside. "It had to be a \$40,000 toilet," she exclaims, describing "the king of toilets." "Everything was on a track. The toilet went up and you could adjust the height of everything... It was in a damn train station!"

True accessibility had been rare in Jason's life, especially living in the US, where accessible designs are often neither thorough nor valued. "In Prague they don't

have the ADA [Americans with Disabilities Act] like we have, but they have common sense," says Adele. "Over here, when they want to make something accessible, they do it cheaply. Over there, if they want to make something accessible, they do it so that it works for the person."

The pursuit of barrier-free and universal design has become both a necessity and a passion for Jason. A wheelchair user since the age of 11, he lives in a world where solutions to his needs around mobility are rarely well-developed. Harnessing the ability to redesign buildings and devices is a tangible route toward empowerment for the aspiring draft architect—transforming hardship into constructive acts. Yet, within the field, Jason has continually struggled against physical and social barriers. "Just

because I'm in a wheelchair, I've had to spend a lot of time proving my cognitive abilities," says Jason. "I think that's one of the major misconceptions. Especially now that a lot of people are graduating from college." Against societal preconceptions, he continues to fight for his dream of an influential career in architecture.

Back at his home, in Columbia, Maryland, Jason's eyes rest firmly on his laptop screen as he works hard to master a new virtual drafting program. "Most design happens digitally now," he explains. "But when I was applying for school and jobs, I would be asked to provide hand-drawn sketches... I obviously couldn't do that." Getting accepted to the University of Maryland was no small feat for Jason, but it paled in comparison to this past year when he

graduated. "Finishing my bachelor's degree was life-changing," says Jason. "I feel like it was a true test for me, and I passed."

To celebrate "passing the test," Jason and Adele are busy planning his graduation party, which coincides with his 33rd birthday. Jason was first diagnosed when he was four, in 1988. "At that time there was not much known about Duchenne other than the name of the disease, that it usually affects boys, and that they're usually dead before they reach 15 or 16," recalls Adele. In 1989, geneticists discovered the gene sequence that caused DMD, and in the decades since, research has grown phenomenally, leading to advances in management and treatment, but as of yet, no curative measures. Whether they find a cure or not, Jason dreams of helping create a world better suited to his and other people with disabilities' needs.

The inspiration to apply to an architecture program came from Jason's own experiences with accessibility issues as well as his innate desire to build. "When I was a kid, I always wanted to do something in building, because my favorite toy was always Legos," says Jason. "I think that's where it all started from." As Jason's needs progressed, his home became a venue for trying new layouts. To make Jason's abode more comfortable and utilitarian, Adele and an uncle did much of the renovations themselves, which helped inspire Jason to try out the process of designing a space.

For his college entrance essay to UMD, Jason studied the life and work of Charles A. Cofield, a quadriplegic architect, who graduated from MIT and UCLA, and worked for the Los Angeles Housing Authority, bringing better housing options to low-income areas of the metropolis. Studying and learning to identify the intersections of ableism, urban planning, and design helped spawn Jason's interest. He also became

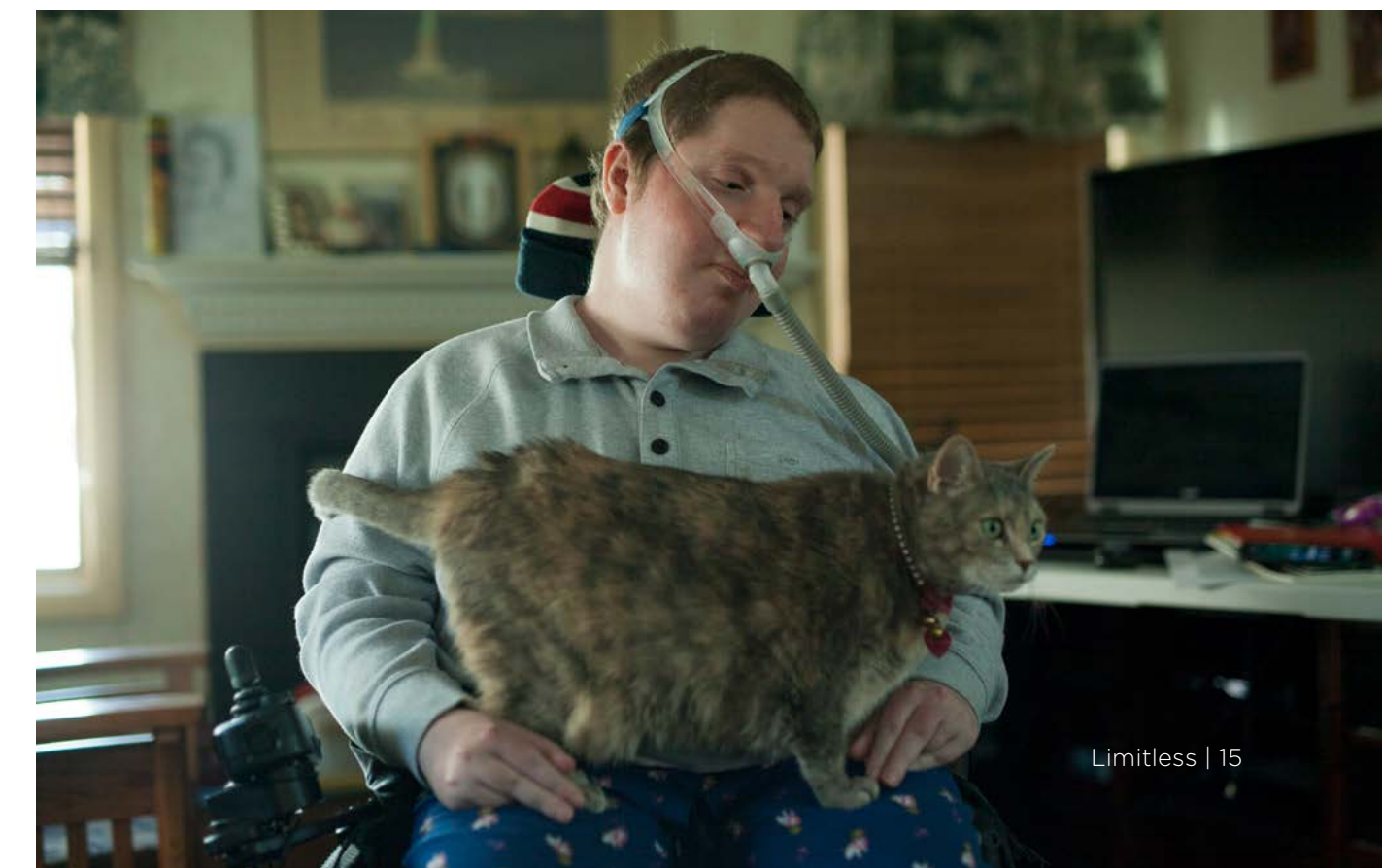
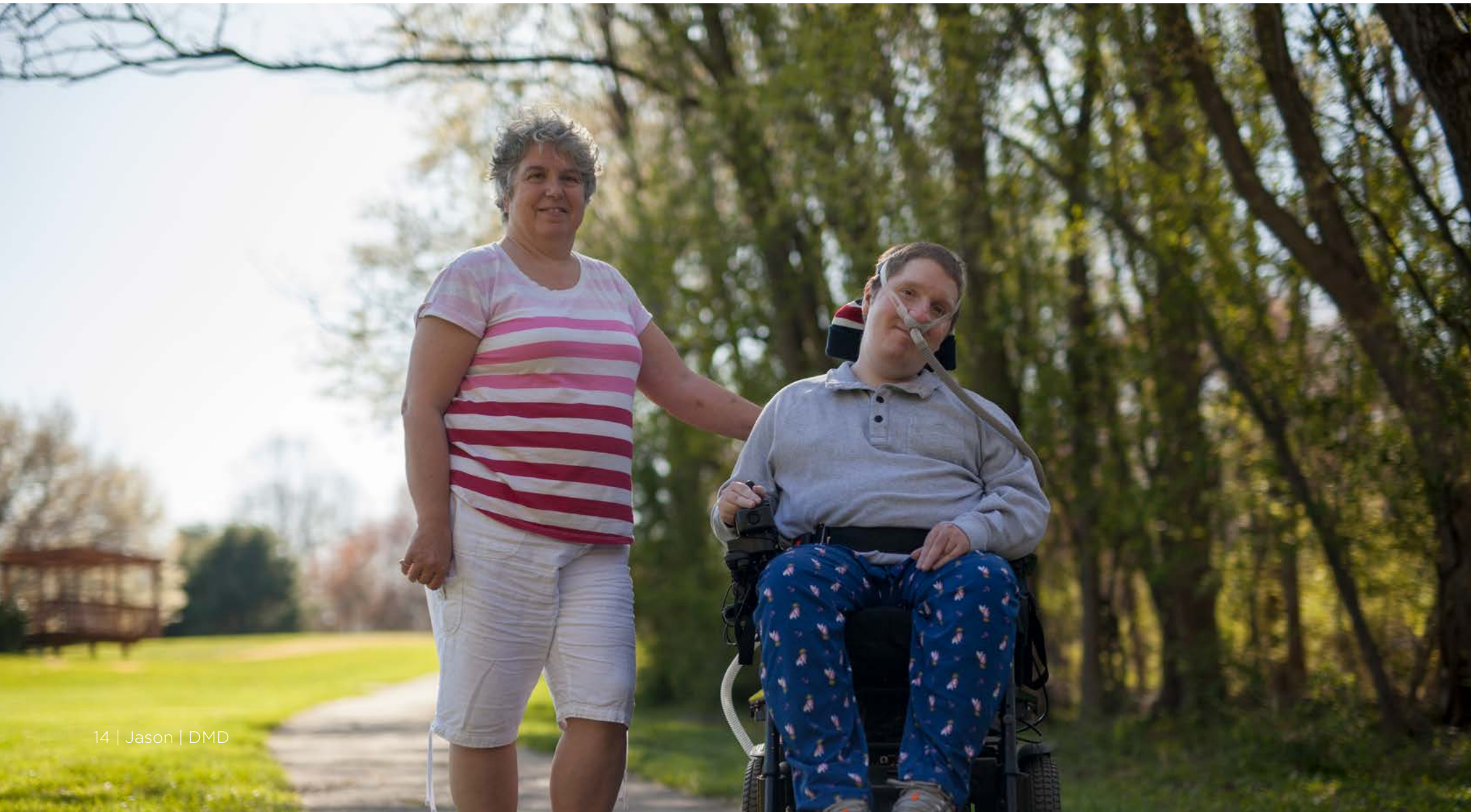
enthralled with the work of the influential architect, Michael Graves, who started using a wheelchair in his last decade of life—leading to a flurry of new architecture—before passing away in 2015.

"There aren't many disabled architects," says Jason, discussing the lack of accessible design being done by individuals who rely on them. From his disposition, Jason sees the opportunity to offer something to the field that few others can: chiefly, first-hand knowledge of which barrier-free and universal designs work the best for people in power wheelchairs. "A lot of architecture firms deal with healthcare buildings," he explains, noting the extensive experience he's had navigating hospitals. "I think I would be able offer that industry something that it usually doesn't have. They don't have anyone who works and designs from my point of view." Using virtual environments, Jason is now able to design entire structures, devices, and urban spaces that can be fully explored on a computer before physical models are built. Mastering new technologies is crucial for Jason to meet his goals. "My main focus now is to create more adaptive, accessible, universal, and barrier-

free designs. And there's a very, very, very small minority of the architectural world that addresses that."

Even in some of the most progressive cities, like Prague and Berlin, Jason still sees room for improvement. "It's hard to find a [hotel] room that has enough power outlets to charge my equipment," he says. Jason uses a non-invasive respirator around the clock, combined with his power wheelchair, a powered air-mattress that he sleeps on, and a whole host of specialty machines to support his health on a daily basis. "At the hotel in Berlin, they gave us a king-sized bed," he says, chuckling from behind his respirator. "I guess they thought we could've been a couple."

"Sometimes we're like a mother and son, and sometimes we're like an old married couple," Adele quips in her Bronx-born accent. Her loquacious and fervent demeanor has served the family well over the years, as she grappled with the implications of DMD, sought out resources and treatment, and supported Jason in his day-to-day needs—almost entirely as a single mother. "We spend a little too much





time together,” admits Jason. To support the family financially, Adele became Jason's nurse through Maryland's Developmental Disabilities Administration, getting paid for her son's demanding at-home care-taking. “He was the cutest baby I ever saw!” Adele reminisces, as Jason rolls his eyes. She goes on to tell us how Jason and his older brother, Josh, were often confused for girls when they were toddlers, because they had such long eyelashes. Jason and Adele's sardonic chemistry is unmistakable and there is no lack of jeering between the two, although underneath, it is clear that there is a solidarity and love that few could fathom.

Within the Duchenne community, the mother-son duo have found themselves a sort of model of their own—bringing

important information to newly diagnosed families, and telling their story. “It knows no socio-economic boundaries,” says Adele. “It hits rich and poor—many of the families who have Duchenne are low-income, and they don't have an excess of time to investigate on their own.” She and Jason are elated to help answer many of the questions that were simply unknowns when he was first diagnosed. “I've spoken at Parent Project Muscular Dystrophy,” says Jason. “I've done a lot of speaking. My neurologist speaks to a lot of college graduate students at Hopkins. Every so often, she invites me to speak with them.”

As Jason remains focused on his drafting prowess, hopefully leading to a career, he continues to battle the physical effects of

DMD. In 2001, he underwent spinal-fusion surgery to correct his severe scoliosis, which was affecting his lungs, and now has transitioned to using a non-invasive respirator full-time. However, his overall health is rather uncanny, as many younger men he has befriended in the community have passed away in their youth. “It's tough to deal with.” Jason ruminates about losing friends in the DMD community. “It reminds me of my own mortality, with maybe some feelings of guilt mixed in: How come my health is still decent? In the same breath, friends dying helps me stay motivated and keeps me moving forward. There's a lot on my plate that I want to do in however much time I have left. I wanna make that time special.”

