



**“I want to be
as independent
as possible,
while I still can.”**

Tayjus

Born October 1995 | Cambridge, MA

Living with DMD

On a freezing day in Cambridge, Massachusetts, Tayjus drives his wheelchair up the ramp of Quincy House at Harvard University. The wide, heavy doors open automatically for him, but they haven't always been so welcoming. For two years, he advocated for a scanner that would read his student ID and open the doors so he could enter his own dormitory. His request was simple: “I’m a student in a wheelchair and I don’t have use of my arms. I need a way to enter this building.” After years of countless emails and phone calls, the university finally installed the requested scanner. Tayjus has been opening doors for himself and others ever since.

Tayjus lives with Duchenne muscular dystrophy (DMD), a genetically inherited disorder characterized by the progressive degeneration of muscles. Boys who are diagnosed with DMD appear to be born with normal muscular function, but soon lose their strength, beginning in their legs. Tayjus was diagnosed when he was five. He’s unable to recall the early days when his parents say he fumbled and tripped while other kids ran, but vividly remembers the moment he got a wheelchair. “I was 11, in sixth grade, and it was getting harder to walk. I was very resistant to a wheelchair. One day when I stepped on a shoe, my ankle twisted and my tibia snapped.” The doctors gave him a manual wheelchair, but he insisted on walking. At 14, he broke a shoulder bone when he tried to walk a short distance and fell. It became dangerous for him to walk at that point and he started using a power wheelchair.

A power wheelchair gave Tayjus more independence. He zipped through crowded hallways and lunchrooms, navigating school like any other kid. "In high school, I didn't think about my disability that much. I had a good group of friends and we had been friends forever. We were the academic types. I didn't have to give up things like

sports," he says laughing, "because we mainly just played video games."

As he excelled through high school, Tayjus dreamed of attending an Ivy League university, where his bright mind and curious nature could continue to flourish. His college entrance essay focused specifically on DMD,

and how his disability imbued him with a passion for social justice and a commitment to advocacy. His acceptance at Harvard was a moment of immense pride for Tayjus and his family. He was also nervous. What would it be like to have a stranger dress him and feed him? Would he be able to navigate the streets of a metropolitan city? Harvard

"People were nice, but interactions were forced, not meaningful. If I made a friend in another dorm, I usually couldn't visit them because their dorm was not wheelchair-friendly. If people said, 'Let's go out to lunch!' and I couldn't go, I'd come back to my room. I was trapped in my dorm. Alone."



seemed a universe away from the quiet, tree-lined New Jersey suburb where he grew up.

“My dad found an article about two girls with muscular dystrophy at Harvard. I met one of the girls and thought, ‘If they can do it, then I can do it too.’” For a month-and-a-half of Tayjus’ first semester, his mom stayed with him until he was settled into a new routine. Then one day he told her, “I think I’ve got this.” With a sense of pride greater than her concern, his mom returned home, leaving her son, for the first time, truly on his own.

Tayjus’ sparsely decorated dorm room, with its exposed concrete block walls and minimal windows, is contrasted by the lively and colorful way he talks; his conversational style is punctuated by expressive hand gestures and smiles that reveal his boyish dimples. He has control of the muscles in his hands as well as his head, neck, and face. His PCAs (personal care assistants) live in a room attached to his living space. They use a lift to assist him with transfers from his bed to his wheelchair; they provide physical support with eating, getting dressed, and using the bathroom. The PCA schedule, scribbled on a dry-erase board, reads as if Tayjus runs a small business, which in a sense, he does: He hires and trains his employees, manages conflicts, juggles complex schedules, and approves timesheets. In general, PCAs do not accompany him to classes or social outings. “It changes the dynamic when there is another person around. I want to be as independent as possible, while I still can.”

The Harvard campus proved to be a huge challenge. “It’s really backwards here. Only two out of twelve freshman dorms are accessible. All the classrooms are accessible, but not all dining rooms are accessible.” For three years, Tayjus has advocated for another card reader to

operate the elevator in his dorm. To date, his attempts have been unsuccessful. “I wait at the elevator—sometimes for 15 minutes—for someone to come by and press the button,” he says, admitting his frustration at how unresponsive the university has been to his needs.

Making friends at Harvard was also difficult. The stigma surrounding disability was real. “People were nice, but interactions were forced, not meaningful.” Accessibility compounded the problem. “If I made a friend in another dorm, I usually couldn’t visit them because their dorm was not wheelchair-friendly. If people said, ‘Let’s go out to lunch!’ and I couldn’t go, I’d come back to my room. I was trapped in my dorm. Alone.”

Tayjus’ expression changes from a furrowed brow to a wide charming grin when he talks about the friends he eventually found. “I made a friend group and they were mostly international. One of my really good friends is from Uganda, another is from Pakistan, and one is from the country of Georgia. One guy, who is my best friend, picks up on my needs. He zips my jacket and wipes food if I spill. Other people have seen that and learned from him how best to help.”

At the foundation of what makes Tayjus’ life function is his dedication to keeping himself healthy. As is typical in men with DMD, his lungs are a fragile ecosystem, susceptible to complications from the common cold. Respiratory infection can be fatal. During his second semester of freshman year, Tayjus contracted pneumonia. With fluid-filled lungs and a raging fever, he was bedridden for two weeks and required three rounds of antibiotics. “The doctor said my lung function was a lot lower than it used to be. He said I had to use a cough-assist machine twice a day, even when I was not sick.” To demonstrate, Tayjus asks

for the mask to be placed on his nose and mouth. The machine sounds like a vacuum, forcing him to inhale first, and then suction out a powerful cough, to dislodge any phlegm or mucus built up in his lungs. “It’s hard to cough on your own with Duchenne. I do this once in the morning and once at night. If I get sick—the minute I get a scratchy

throat—I use it aggressively.” He admits he gets scared when he sees older men with Duchenne who are trached or wear a BiPap (or another breathing machine), full-time. “I do whatever I can to preserve my lung function.”

Part of Tayjus’ advocacy involves speaking with newly diagnosed DMD families. “When

a child is first diagnosed with Duchenne, the parents think about their kid not walking or playing sports. They are worried about how long their child will live.” He reminds them that this is the best time for a kid to be born with Duchenne because there are so many options. He tells people about the dozens of companies that are working to improve people’s lives through the development of

innovative therapies, and the creation of devices to help support the health of people living with DMD. “It gives them hope,” he says.

The ideals of biotech and pharmaceutical companies resonate with Tayjus’ professional goals: to extend and improve the lives of boys and men living with DMD.

“I made a friend group and they were mostly international. One of my really good friends is from Uganda, another is from Pakistan, and one is from the country of Georgia. One guy, who is my best friend, picks up on my needs. He zips my jacket and wipes food if I spill. Other people have seen that and learned from him how best to help.”



He plans to work in public policy, lobbying for access to care for all individuals with Duchenne. Already, he has worked closely with Parent Project Muscular Dystrophy, having served on several advisory boards and advocating on Capitol Hill. He also has

brought a patient perspective to a number of pharmaceutical developers, working as an intern for two companies who are researching drugs for DMD. When asked if he'd ever consider running for office, his eyes hinted at a sparkle. "I don't know...

Maybe!" Today, Tayjus sees the many challenges ahead of him as doors he has yet to pry open. With his education, work as an advocate and his personal experience living with DMD, he is uniquely poised to unlock each one in due time.

