



Siddharth

Born May 1995 | Cupertino, California

Living with DMD

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Siddharth's day starts before the sun rises, when his father wakes him and starts the laborious task of getting him ready for school. "I need to get up early to get him to the bathroom first," describes Satya, Siddharth's father. "The whole process takes almost three hours. I don't get hung up on that. I just get ready and go."

One crucial tool for moving Siddharth is the ceiling-mounted track lift which traverses from Siddharth's bedside to his closet, his bathroom, and the outside hallway. Satya carefully connects the straps to support Siddharth's weight, and with the push of a button is able to safely transfer him to his power wheelchair. Satya manages much of the morning's tasks with the help of this machine and his own strength. Bracing his lower back, Satya uses a pivoting motion to move Siddharth from his stander (a therapeutic standing apparatus used for stretching) back into his chair, utilizing momentum to successfully complete the transfer.

Siddharth and his family endure this routine Tuesday through Thursday, in order for him to get to class at San Jose State, where he is finishing up his

bachelor's degree in communication studies this spring semester. He has his sights on a master's degree in the coming years. "Before starting in communication studies, I only just discovered my passion for writing," says Siddharth. "Now, my aspirations are to work in the media industry, for NASCAR, as a reporter writing relevant articles about each race throughout the season." For an adult living with Duchenne muscular dystrophy (DMD), these sorts of trajectories represent a new chapter in the story of the

neurodegenerative disease, which once predominantly robbed young men of the ability to ever consider having a career. Siddharth's story is full of inspiration for young men with the disease, who undoubtedly hold similar aspirations and capabilities.

Siddharth was born in Hyderabad, India, but moved to the California coast at the age of one. Satya and his wife, Nishi came to the US for economic opportunity and for the

chance to live near family. "I worked in IT," recalls Satya. "I wanted to come here, and my job agreed." Nishi had extended family in California. "I have nine siblings," she says. "And seven of them lived in the US already. We were actually the last ones to come here."

Around the age of five, Siddharth started to show early signs of DMD. "In 1999, he was about to go into kindergarten," remembers Satya. "He was at summer school and the psychologist noticed that he wasn't walking straight—that he was not keeping up with his peers—and told us to take him to a neurologist." The neurologist ordered a blood test for Duchenne. Within weeks, the family's future was forever changed as they learned that Siddharth had been born with a severe, life-limiting disorder, with few treatments and no cure.



"In the beginning, I was not ready to accept it," says Nishi. Neither of his parents had heard of DMD and they couldn't bring themselves to talk about it openly, even with other family members. "It took several years to speak to other people about it," says Satya. "For me, at least, it took a lot of time." Nishi and Satya grappled with the implications of the disease within their family and community, but ultimately responded proactively, seeking resources and guidance from the Muscular Dystrophy Association (MDA). "We

got this book [A House for All Children] that helped us redesign our house," explains Nishi, pointing out the wider doorways and hallways. "That way, we were ready for the future."

For Siddharth, realizations about his condition came with his diminishing physical abilities. "I gained an understanding of it a few years later, when I started to see that there were a number of things I could not do at the pace of other kids." He struggled

to make friends and found himself socially isolated. "That was another frustration for him," says Satya. "He would correlate that with his diagnosis. He would say, 'Because of my diagnosis, I don't have any friends.'"

The struggle for acceptance, both of his condition and amongst his peers, was central to Siddharth's adolescence. "When I started to use the wheelchair full-time—that is when I started to adopt a more positive outlook. It built my confidence, and I was able to make a few more friends." Likewise, teasing and bullying lessened as Siddharth's condition became more "visible" to his classmates. "Around that time I started to notice people began to be more friendly," he says. While it aided him socially, the transition to using a wheelchair full-time also symbolized the irreversible path of DMD. Satya and Nishi responded with overarching support and kindness. "Early on, he asked if it was going to be like this forever," remembers Satya. "We told him, 'Yes, it is going to be like this forever. You'll always be in a wheelchair, and we will always love you.'"

Siddharth accepted his reality, and at the same time, found ways to embrace it. From his earliest years, Siddharth held an infinite fascination with automobiles: from miniature toy cars and trucks, to emerging technologies, and professional-level competition. He began dreaming in circles. Images of race cars careening around a cambered tarmac—rubber melting onto pavement, roaring engines, soaring speeds—fueled an unquenchable curiosity. Now, each weekend, Siddharth sits with his family and friends and watches live NASCAR races on the family's big-screen TV, cheering on their favorite drivers. Siddharth also fostered a passion for playing racing video games on his PS4, and has had the opportunity to drive himself, thanks to adaptive hand controls. Siddharth took driving lessons in 2014, almost earning his driver's license and it remains a goal for him. Even still, the enjoyment of watching NASCAR continues to be a major outlet for Siddharth.

"NASCAR started for me in 2008," recalls Siddharth. "I got a chance, through the

Make-a-Wish Foundation, to meet driver Jeff Gordon." This piqued his interest, and along with Satya, the father-son duo began watching and attending races, once traveling to the famous Indianapolis Motor Speedway. "Jeff Gordon was my favorite driver for a while, but he retired in 2015," says Siddharth. "Now, I root for Chase Elliot." Satya is quick to rebuke. "Jimmie Johnson is the best driver. I root for him." He pumps his fist in the air in an unexpected jeer of excitement, from the typically mild-

mannered gentleman. Their rivalry is alive and well.

Likewise, power soccer, a sport that highlights the abilities and skills of power wheelchair users, came into Siddharth's life in his late teenage years, providing him with an important competitive outlet, as well as a way to bond with others. "It has been a source of empowerment for me," he exclaims. "I view power soccer as a way to showcase my true abilities and uplift





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against pessimistic attitudes.” He plays on the Steamrollers, a San Jose area team, that travels across California for games, as well as to the national tournament, in Indiana, where the team achieved second place in their division last year.

New passions unearthed new strengths for Siddharth, and he soon fostered a desire to espouse the lessons of living with DMD as a way of radiating positivity to others. “I refuse to let my disability stop me from pursuing my passions and living a meaningful, accomplished life,” he states profoundly. “I would say what guides me is always maintaining a positive attitude and remembering that my disability can be my greatest ability. Sometimes, a disability can lead you to focus on what you can’t do, but I believe in maximizing what I can do. It’s an important way of dealing with my situation in an effective way.”

Siddharth speaks slowly, and responds at his own pace—pausing before each elucidating statement—the impact of his deliberate words given time to linger in a listener’s ears. While Siddharth is clearly a bright young man, he struggles with speech and language, and he has worked hard to fully develop these skills. As he strives to get into the media industry as a writer and commentator, these are hurdles he is poised to overcome. “The oral aspect is as important as the written aspect. To improve my speaking skills, I am currently attending a local Toastmaster’s group.” The meetup has given him a chance to practice public speaking. “Developing my oral skills and continuing my education will maximize my abilities, so I can realize my dreams of working in the media industry,” he relates.

Writing, too, is crucial to Siddharth as a tool for learning and self-expression. He wheels into the at-home office to start this weekend’s assignments. Nishi helps carry some of his books and sets them down on the broad desk. Siddharth is still able to use his hands to type (something relatively uncommon for men his age with DMD), and he makes avid use of this ability. A couple years ago, he started writing for the MDA, starting a blog called “Spreading the Wings of Life,” where he muses on life’s lessons. Writing and communicating have become a powerful act for Siddharth, and one he can tackle much on his own; a mark of independence for a young man who finds himself increasingly dependent on others.

Knowing the harsh prognosis, the family spends each day focused on caregiving and necessary tasks, avoiding more pernicious questions. “I don’t worry too much. I do my routine, and then, all is well,” says Satya, intoning his personal mantra. “That’s why I don’t focus too much on the future and at the same time, I don’t think negatively about the future.” The coming years will bring new challenges to this family even with the potential for groundbreaking treatments. “I have hope that something will come up,” says Siddharth of new DMD research and drug developments. “I don’t regularly look at research updates because if it’s meant to be, it will work out. I focus on what I can do right now.”