

Amin

Born June 2006 | Los Angeles, CA

Living with DMD

There is something striking about Amin's eyes, as if they are two deep jade pools of water that pull you into the quiet wisdom that streams from them. At 11 years old, his presence is poised, elegant, and stoic; until you reach his toy car collection and he lights up like the bright child he is, talking about Lamborghinis, Bugattis, and the fastest vehicles in the world. Amin's parents, Mastrooreh and Ali, open their home with gestures of hospitality—offering house slippers to their guests so they can take off their street shoes. The family emigrated from Iran in 2015, bringing the beauty of their Persian culture with them. A perfectly cooked three-course meal sits waiting at the dining table, with cups of Persian tea, and treats for dessert to follow. Instead of cooking a traditional Persian feast of *khoresh* (stew), Mastrooreh baked lasagna and a cheesecake to better cater to American cuisine. She still included a traditional Persian side-dish of saffron-rice with cranberries, and *tadik* (a crunchy rice delicacy).

Ali, Mastrooreh, and Amin live in an apartment in Beverly Hills with panoramic windows that let in the light and vistas of the surrounding hills and city life below. While sharing their delicious meal, Mastrooreh and Ali gracefully describe their most difficult

journey—their son's Duchenne muscular dystrophy (DMD) diagnosis and their emigration to the United States, to find the best available treatment.

Back in Iran, Amin was a happy child, growing up in relative comfort. Ali was an experience physician who specialized in emergency medicine, while Mastrooreh, a painter and illustrator, taught art at the local university. Coming from prominent families, they had more-than-sufficient income. They lived in a beautiful home in Tehran, surrounded by Amin's grandparents and a large extended family.



“Iran is very rich in natural resources; oil, gas, and gold. However, the most beautiful resource in our country is the people. There, we supported and depended on family.”

When Amin was five years old, his kindergarten teacher expressed concern about Amin’s physical limitation because he couldn’t run as fast as his classmates. “She asked us to visit the orthopedic doctor,” remembers Ali. “We did some blood tests that showed Amin had problems in his muscles. The doctors sent his blood samples to Germany and it confirmed that Amin had [Duchenne] muscular dystrophy.”

Mastooreh found a DMD organization in Iran that held meetings twice a year.

Fortuitously, a meeting was scheduled the same week they received Amin’s diagnosis. The family attended the meeting together, and Amin met older boys with DMD who used wheelchairs. At five years old, Amin could still run and walk. “In that moment,” Mastooreh remembers, “Amin figured it out. He understood the reason why we were there next to all these people who have Duchenne.” Amin said he adapted quickly to the realization. “He was always very accepting,” says Mastooreh with a tear in her eye. She continued to bring Amin with

her to the meetings so he could see the boys older than him with power wheelchairs.

Amin participated in physical therapy and was swimming nearly every day, but in Iran he did not have access to treatments or clinical trials. A doctor, Ali had access to information about emerging therapies and was determined to find the best for his son. “I always follow new clinical trials in the US and I knew one was starting soon.” He decided to attempt the long journey with his family to travel to the US. “This medicine is

important for all the world,” says Ali. “And it is only in the US and Europe.”

Obtaining green cards for the whole family was a huge hurdle. They hired a lawyer to help them. “The only way our lawyer could get our green cards was to make an investment for an EB-5 Immigrant Investor Program, with a payment of \$500,000.” After three years they were still waiting in suspense for a response—with no green cards in hand. “We were concerned about missing the trial and we couldn’t wait for

the green cards’ long processing time. Amin was losing his ability to go up and down stairs. We decided to come to the US with a medical visa.”

The family traveled to Dubai to request a medical visa from the US Embassy. After a year waiting, Ali was finally granted a visa but Mastooreh and Amin were not. Ali emailed several embassies throughout the world to request help, but resigned himself to the fact that he might be leaving for America alone. Just a few days before



“In our country we were dependent on a huge family. But we couldn’t tell them. They just knew we left; they didn’t know why. We could not believe or imagine we would be moving to America.” –Ali

Ali’s scheduled departure Mastroeh and Amin miraculously got their visas and Ali rescheduled his flight to leave a week later, this time, with his wife and son. Without telling family and friends besides their own parents, they rapidly packed a few suitcases and left Iran. It was a gamble. Mastroeh and Ali didn’t know for sure if they would be leaving permanently or what exactly they would find. They arrived in the US in March 2015, and a year later, in March 2016, they received their green cards.

The family received medical visas based on Amin’s appointment with John Hopkins

University in Baltimore. However, Ali’s cousin recommended they visit UCLA and then decide their next plans. At UCLA, they met experts researching DMD.

“I believe the US has the best medicine and safest trials in the world,” says Ali. “There are seven billion people in the world looking to the US for new medicine. Everything is here for patients: new medicine and new clinical trials.” In Iran, university budgets do not have much funding available for research, studies, treatment, or new science. “This is hard for people who have to live and can’t move to another country,” says Ali.

“We decided to move to a country that we never saw; that was huge; and far, far away. We took a risk!” exclaims Mastroeh.

Amin started fourth grade in the United States. “When I started school I didn’t know any English,” he recalls with a smile. His father remarks, “After almost three years, he’s better speaking than us!” Mastroeh chimes in. “Amin’s school homework is homework for all of us too.” They all laugh. Then, the conversation turns to a more somber tone, as they talk about Amin taking his last steps. He was nine years old, and the family was out at the UCLA pool

“When we were in the emergency room, I was crying, crying. Amin said, ‘No mom, don’t cry. God is very strong. Trust to God. Trust to God.’ He makes *us* strong.” –Mastoofeh

for physiotherapy. When the time had come to leave, Amin was waiting by the car and suddenly lost his balance. He fell, breaking his right femur in two places. The fractures required surgery, which was long, difficult, and very stressful for the family. “When we were in the emergency room, I was crying, crying,” recalls Mastroeh. “Amin said, ‘No mom, don’t cry. God is very strong. Trust to God. Trust to God.’ He makes *us* strong.”

Since that incident, Amin has used a wheelchair, which he remains positive about. He especially enjoys his ability to maneuver the wheelchair at fast speeds.

This developed into a love for sports cars and anything that moves fast as well as power soccer, an adaptation of soccer for power wheelchair users. He recently joined a power soccer team and it is the highlight of his week. At Sunday practice in the gymnasium, the basketball court is split in two halves for the junior practice and the varsity practice. Amin started out on the junior team, practicing passes and general ball handling. At the far side of the court, the varsity team moves with great speed and agility in full scrimmage, with noises rising of competitive sportsmanship and the occasional clang of a collision. Amin moves

calmly, swiftly and precisely, a glimmer of excitement shining in his eyes. From the back of his power chair hangs a piece of paper, “AMIN #2, LA AVENGERS” with a red Bugatti sticker he has pasted below.

Like the newest cars, Amin and his parents look toward groundbreaking biomedical technology to hopefully treat DMD in his lifetime. It is a source of fascination for all of them, who remain determined to help Amin get the best treatments available. This willpower has led them on an incredible journey, one that has taken him halfway around the world in the search for a cure.

