Kyle

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A Life with DMD

The oversized soccer ball shoots across the polished wooden floor as the wheelchair athletes practice their passing game. Hands on his hips, their head coach, Armando, explains different strategies and positions from which to send and receive a pass—the architecture of a sport called power soccer. The players listen closely from their power wheelchairs. Among them there is a vast range of age and life experience, from boys and girls barely older than seven, to adults in their 30s and 40s. They coalesce each Sunday in a gymnasium in Glendale, California, to practice the sport they love.

Kyle quickly maneuvers his power chair into position to demonstrate the different ways to pass. His experience is a gift to the team as an eight-year veteran of the sport and the head coach's son. With striking agility he makes precise moves with his chair and volleys the ball to the other players, giving them an opportunity to understand the necessary reaction time, the chairs' turning radii, and the correct speed—all instigated by the deft moves of one hand on the chair's pivoting joystick. With each pass, the joy of the sport emanates from Kyle in his furtive smile.

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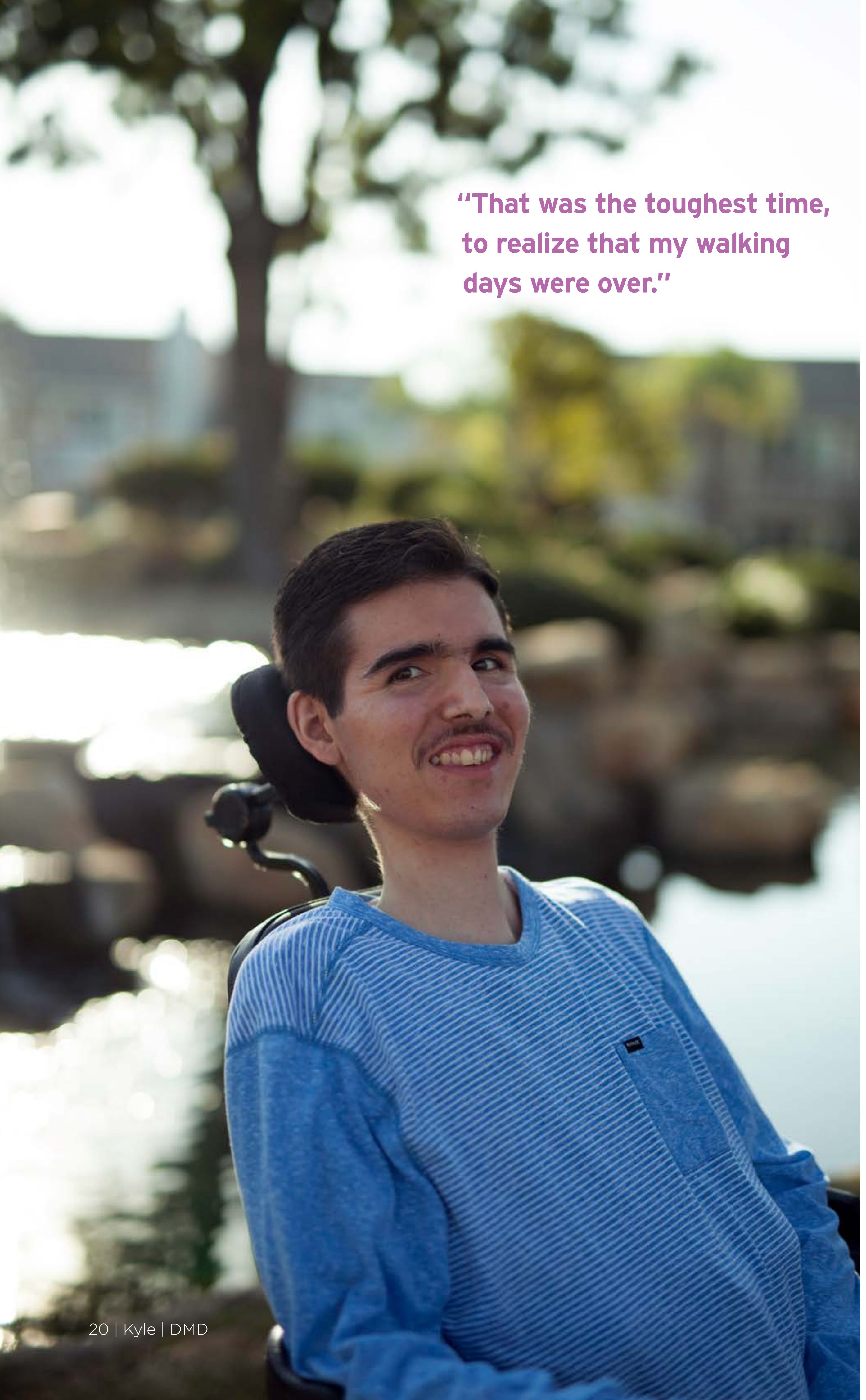

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"About six years ago, they started making a wheelchair strictly for power soccer," Kyle explains. He displays his chair, called the Strike Force, and its swift capabilities. Just a minute gesture with the control stick unleashes a rapid, aggressive movement from the chair, allowing for powerful "kicks" by utilizing a welded cage around his footrest. "It's lower to the ground. It has more torque. You can turn quicker. It makes the game more fast-paced." The Strike Force chair is an emblem of how far this sport has come, from grassroots beginnings on vacant basketball courts in France and Canada pre-1980, to an internationally recognized sport with its own tournaments and leagues under the banner of FIPFA (Fédération Internationale de Power Football Association).

The progression of the sport has mirrored the advancements for people who use wheelchairs around the world, providing an outlet for competition and teamwork. It has helped defy the falsely-portrayed archetype of the sedentary wheelchair user, of the "disabled" person lacking any recreational pastimes. For Kyle, who was diagnosed with Duchenne muscular dystrophy (DMD), a neurodegenerative muscle disorder, at age six, the sport is far more than a passing hobby or weekend diversion—it is a pivotal event he looks forward to each week with pride and aspiration.

"It's been pretty life-changing for me," he relates. "To have an activity to do—an outlet." Kyle was born into a family ensconced in the joy of sport. "He's always liked sports," says Armando, who himself fosters an enthusiasm for athletics. "When he was five years old, he played basketball and t-ball." During games and practices, Kyle struggled to match his teammates physically. "I noticed when the coach would have him run around the bases, he was the slowest one. When they would run twice around the bases, the other kids would lap him." His parents brought their concerns to his pediatrician. "He had really large calves," remembers his mother, Sandra. "With Duchenne, your muscles are enlarged and then slowly waste away. I have the same problem, so I thought, that's just what I have. Turns out I'm a carrier."

Months of genetic testing revealed that Kyle had been born with DMD and he and his family began to cope with the facts of the terminal condition, which still has no cure. They learned Kyle's life expectancy was severely truncated (prognosis was late teens to early twenties, although it's extended by almost a decade now.) Dishearteningly, Kyle accepted that he would no longer be able to play sports, or so he thought. As the disease progressed, his muscles shrank, making daily activities more challenging. On his first day of school in seventh grade, Kyle felt unusually weak, and during the long walk from the parking lot to his middle school in Yorba Linda, he fell and couldn't get up. "One day I was walking and it was fine," he says. "Then, I just felt so weak. It happened so quickly." Sandra rushed over to help him up and make sure he was okay. Kyle would rise to his feet again that day, but with the knowledge that those days would be numbered. "That was the toughest time, to realize that my walking days were over."

Upon entering eighth grade, Kyle started using a power wheelchair, and he has not walked since. His friends and teachers stepped into his life to help facilitate new activities and show him love. "I was very lucky in that regard," reflects Kyle. "I had

friends that really looked out for me and helped me out. Some of the best friends that anybody could ask for." With a push from a supportive teacher, Kyle joined the yearbook staff in eighth grade, and stuck with it until he graduated high school. "I was assistant editor at yearbook for a couple years. Those were some fun times."

Armando and Sandra continued to support Kyle with his day-to-day needs, as well as finding him new activities. Taking him to watch sports became a family bonding experience. Armando consistently went out of his way to score tickets to see Kyle's favorite teams. They would go to Lakers' games in LA, Angels' games in Anaheim, and would even travel to see University of Arizona (Armando's alma mater) football and basketball games. Kyle's sister, Rebecca, was a soccer player and the whole family would travel to her games and tournaments. "I was her biggest fan," says Kyle endearingly. "But I was on the sidelines. I wanted to be independent and in control of the game."

So when Armando and Kyle first read about power soccer and a team based in Glendale, they didn't hesitate to just show up. Upon arriving, Kyle became elated with the challenge of learning a new sport and the potential for bonding with other individuals in wheelchairs. Likewise, Armando saw an opportunity to support his son's aspirations. "The first season, I just helped out as much as possible," he says. When Kyle's coach decided to move to Arizona, Armando saw a ripe opportunity to support his son and others who faced similar hurdles in life. After only two seasons, Armando stepped up to fill the vacancy as head coach, a role he has embraced for the past seven years.

Under Armando's guidance the program has expanded, from including mainly college-aged boys, to now including boys, girls, men, and women of all ages. "We have now grown to three teams." Each team is formed on the basis of age and experience. Armando continues to work at an insurance agency and coach on the weekends. "I work during the week. This is just something for Kyle and other kids who are out there. If I see a smile on their face, that makes me just want to continue doing it. It gives them something to look forward to—to be part of a team. Now they enter these tournaments, with other teams from different parts of the States. It's just awesome. It allows Kyle to meet people and play a sport they just love to play."

"A lot of these kids don't have much of an outlet," adds Sandra, who helps out when she can. "They are a bit isolated, socially. When they come out to play power soccer, it's a whole new world for them. They realize there are people like them." Kyle has formed numerous friendships through his team, which has provided a venue for socially active adults living with mobility issues.

The team has proved to be a more successful social outlet than higher education. Kyle attended a local university to study Journalism for a year-and-a-half, but felt socially isolated. "I decided it just really wasn't for me," he says. Likewise,

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—Armando

with the progression of Duchenne, daily activities had become more laborious. Even the act of eating became challenging, as Kyle's jaw muscles grew too weak to chew his food, resulting in malnutrition. "I have a g-tube now," explains Kyle. "To make sure I am getting enough calories. I was a little blindsided by that, even though I knew others with Duchenne who have the same problem." This recent development added to the list of reasons why staying at home was the best option.

"He would prefer to have his own apartment," says Sandra. "But I think he handles it pretty well." At home, Sandra and Armando prioritize care for Kyle, doing all the daily monitoring and therapeutic measures to help him retain mobility and avoid complications. Kyle understands the necessity of living at home, although he also strives for independence. One helpful measure is employment. Kyle works for his parents at their insurance agency in town, doing IT support for the franchise. "It's pretty simple stuff," relates Kyle. "Simple to you," Armando interjects. Clearly his work is valued and getting out of the house throughout the week helps Kyle avoid feelings of isolation.

Utilizing his prowess on computers, Kyle recently started his own fundraising and awareness campaign, upon turning 23, to find a cure for Duchenne. "I want to raise $23,000 this year," he says. "I know it's a big goal, but in the first month I've raised $3,000. It's a year long fundraiser, so I have time. In my heart, I have this sense that I want to make a difference in the world—not just for me—but for others with Duchenne."

Through Kyle's burgeoning social networks, as well as power soccer, he is learning valuable lessons from the broader community as he enters adulthood. "The main thing is knowing and seeing how people deal with different disabilities," says Kyle. "How they handle everyday life. How they are able to adjust and cope with it. They are such inspirational people. You can pretty much just do anything you put your mind to. It gives me a ton of confidence."

Back on the court, Kyle's poise is notable. His favorite position is wing, opportunistically trying to sneak around defenders for a clear shot at the goal. His aggressive, winding course forces the defense to re-adjust, scooting backwards at high speeds. Kyle darts between two defenders and sets up with his back to the goal—the standard pre-kick position. He fakes to the left, pulling a defender out of his potential shooting path. Suddenly, a pass comes from the center and in a blink-of-an-eye Kyle whips his chair around sending the ball careening toward the goal.

On July 3, 2018, while traveling home from a national conference cup in Indiana where he had been competing with his fellow Vaqueros, Kyle went into cardiac arrest and had to be airlifted to the hospital. He was placed in intensive care for several days in Colorado, where he then passed in the evening of July 8th. Kyle was a courageous and fierce athlete, with an unwavering goal—to "knockout Duchenne" and improve his quality of life, while helping others. Among many of his virtues, Kyle is remembered for his joy and generosity. He continues to live on through his many friends, family members and teammates, as well as through his fundraising for research and the donation of his liver and kidneys. We are grateful for his immeasurable contributions and for being a trailblazer, on and off the court.

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