

COMMUNITY AMBASSADORS



Empowering families.
Fighting Duchenne.

BRUCE WARD | ROYAL, AR

Relationship to Duchenne: Father

Bruce is the father to Gavin, a 12-year-old with Duchenne muscular dystrophy. In Bruce's spare time, he reviews Duchenne muscular dystrophy research and communicates with other Duchenne families. Over the years, Bruce has appreciated connecting with other Duchenne dads and communicating with Jett Foundation staff.

KATHI COOLEY | PHOENIX, AZ

Relationship to Duchenne: Mother

Muscular dystrophy has been part of Kathi's life growing up. She grew up with her brother Larry being diagnosed, and now her 26-year-old son Tyler. "I saw my brother grow up on a limited family budget and limited to no resources or organizations like Jett to support him or others during those years," says Kathi. Recently, Tyler participated in Jett Foundation's Jett Giving Fund program. "An accessible vehicle has changed my son's life," she says. As a Community Ambassador, she is looking forward to joining other ambassadors to continue to reach families in many ways.

RYAN RUSSELL | SAFFORD, AZ

Relationship to Duchenne: Individual affected by Duchenne

Ryan spent 14 years in college earning an M. Ed. in Counseling and Human Relations, and a Ph.D. in Psychology. He uses this knowledge as a life coach to help individuals reach goals and achieve dreams. He is an author, motivational speaker, and entrepreneur. "Jett has amazing programs to help people, be it for emergencies, vans, or Camp Promise," he says. Ryan's unique perspective is that in 2021, he lost his parents and now lives alone with a caregiver on his property. He hopes he can help other people find the help and resources they need to live their full measure of life.

MONICA LOPEZ | RIVERSIDE, CA

Relationship to Duchenne: Mother

Monica, her sons, her husband, and their French Bulldog puppy enjoy going to the beach, going for drives, and eating different types of food. Both Monica and her husband have worked in the medical field for many years, which makes them more aware of available services for Duchenne in California. "When families feel that the need is endless, I wish to help educate them and provide resources. I want to support families emotionally, financially, and mentally," says Monica.

TRACI RICO | CARDIFF, CA

Relationship to Duchenne: Mother

"We find that humor is the greatest medicine," is what Traci lives by as her family has faced an abundance of medical challenges over the years. In addition to caring for her family, which includes her son, Tanner, who is diagnosed with Duchenne, Traci works for a nonprofit that supports families in finding resources for medically fragile individuals. She enjoys education, connecting with moms at Porch Nites, and spending time with her family.

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ERICA HILL | JOHNSTOWN, CO

Relationship to Duchenne: Mother

Erica is a mother to Karissa (8) and Anthony (5). Anthony was diagnosed with Duchenne in 2019 at 11 months old. In addition to Duchenne, he has other complex medical needs. Erica has professional experience in the Durable Medical Equipment Industry and navigation of services for those with disabilities. She is a huge advocate for all special needs and medically-complex children. She is also a parent CNA for Anthony. She currently works for a pediatric home health and medical supply company.

DIANA JOHNSON | GLASTONBURY, CT

Relationship to Duchenne: Mother

Diana, mom of 3, loves spending time with her family. She enjoys practicing yoga, barre, and kick-boxing. Her oldest child, Jordan, was diagnosed with Duchenne. Dana currently works as a human resources professional. She hopes to expand her career to strengthen inclusion efforts in the workplace for employees with mobility disabilities. Diana has been a Jett ambassador for three years and has participated in many Jett Foundation programs. "My favorite events are the family workshops because I gain so much hope hearing about treatment options and upcoming clinical trials." As an ambassador, she looks forward to spreading awareness about Duchenne.

LISA HUNTLEY | KANKAKEE, IL

Relationship to Duchenne: Grandparent

"I feel as though my mission in life was given to me when Ethen, my grandson, was diagnosed with Duchenne" says Lisa. Her grandson is 13-years-old, and was diagnosed with Duchenne at the age of 4. As a caretaker and advocate, Lisa desires to be a voice for Duchenne muscular dystrophy, a support system for others, and knowledgeable for her family. She says "I always participate in Porch Nites, where there is a lot of support and resources. After being a hairstylist for 36 years, I have become a great conversationalist and use that to get involved as much as possible."

MARI SANDERS | FULTON, IL

Relationship to Duchenne: Grandmother

Mari is a mother and grandmother working in education. When her 17-year-old grandson Carter was first diagnosed with Duchenne, her family felt alone until they began their education journey, learning about research and treatments. Mari wants to be actively involved in this learning process for other families. Mari has been an ambassador for three years. As an ambassador, her goal is to share information that benefits Duchenne families and bring awareness of Jett Foundation to the Midwest. "I have made strong bonds with Mothers, Grandmothers, and caregivers. These interactions and instant connections remain strong in my mind," she says.

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ALLYSSA KOUGH | SCOTT CITY, KS

Relationship to Duchenne: Mother

Allyssa is the mother of 9-month-old Joslyn and 6-year-old Brody. The family learned of Brody's Duchenne diagnosis in 2020 and ever since have tried to raise awareness and become as involved as possible with the Duchenne community. Allyssa says, "It is on my radar to host a color run for the Duchenne community and share our story. I could talk about my sweet boy all day long!" She loves the awareness portion of the Ambassador program and feels she can bring friendliness, compassion, and more to the ambassador team!

MARK PARISI | FRANKLIN, MA

Relationship to Duchenne: Father

A dad of two boys with Duchenne, Mark hopes to continue participating in community events and growing the number of ambassadors who are Duchenne fathers. His sons, Caeden and Devin, enjoy participating in Camp Promise, Rare Disease Day, and New England Patriots Training Camp. Mark says "I am very passionate about giving my boys the best life possible and raising awareness for all that have Duchenne muscular dystrophy."

ALAN CHAULET | LEXINGTON, MA

Relationship to Duchenne: Individual Affected by Duchenne

Alan is an Entrepreneur fighting Duchenne. He graduated from Bentley University in 2013 with a Management Degree and since 2014 has been working as the Vice President of All Wheels Up, the first not-for-profit organization in the world to fund research and development for a "wheelchair spot" on commercial aircraft. The organization is working with airline carriers and aircraft manufacturers to make airplanes wheelchair accessible for the millions of people who depend on them for mobility and safe seating.

MELISSA LIDIC | FALLSTON, MD

Relationship to Duchenne: Mother

Melissa is a mom of two. Her 16-year-old son, Owen, was diagnosed with Duchenne when he was only three months old. His diagnosis caused her to pivot into the nursing career she has now. Melissa has been very involved in the Duchenne community, and acted as a family liaison to newly diagnosed families. "After finding Jett Foundation, I quickly realized this was the organization at the epicenter of trying to take care of the FAMILY." She has even made her own Facebook group that connects Duchenne families in Maryland.

LAURA MCRITCHIE | FLINT, MI

Relationship to Duchenne: Mother

Laura is an avid runner, hiker, and an all around outdoor enthusiast. She has a passion for photography, painting, and spending time with her three children. Laura also works as a Health Educator in her community. Her son Noah (23) was diagnosed with Duchenne at the age of 5 in 2003, which was the first time Laura and her family learned of Duchenne. He is her drive, motivation, and inspiration. Some of Laura's favorite memories include speaking to bio pharmaceutical companies, attending the NORD conference, and being a panelist at Rare Disease Day in Boston. As a Jett ambassador, she looks forward to being a presence for those with Duchenne who are not in trials.

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HOLLY ALDERINK | MUSKEGON, MI

Relationship to Duchenne: Mother

Holly is a mom to her 12-year-old son Chase, who is diagnosed with Duchenne. In the community I live in, Duchenne or muscular dystrophy is not something people know a lot about or talk about," says Holly. As a new Community Ambassador, Holly is looking forward to bringing awareness to Duchenne and support for others on the same journey.

SUSAN BUELTMANN | DARDENNE PRAIRIE, MO

Relationship to Duchenne: Mother

Susan's son, Stephen, was diagnosed with both autism and Duchenne at a very young age. Stephen's recent and unfortunate passing has pushed Susan to continue her Duchenne community participation by staying involved with programs like her son was. They enjoyed Camp Promise, Porch Nites, awareness days, and sharing their knowledge with other Duchenne families! "Stephen and I enjoyed the camaraderie of Jett Foundation and its events. Jett Foundation is about the people, not just the science" she says.

BROOKE RIENER | NEOSHO, MO

Relationship to Duchenne: Mother

As a mother to Landyn, a 12 year old with Duchenne, Brooke wants to help other parents and schools understand more about muscular dystrophy. She says "I have my CDA and am CPR certified, but I still would do anything to help other families work through this disease and educate myself even more."

JOSLYN PHELPS | WINSTON SALEM, NC

Relationship to Duchenne: Mother

Joslyn Phelps and her son Jalen were recently diagnosed with Duchenne. After years of fighting to get a diagnosis, and continuing to fight for the correct diagnosis, Joslyn is a fierce advocate. Jett foundation and the Porch Nites saved Joslyn and inspired her to want to help within the Duchenne community. While they are just beginning to understand his diagnosis, Joslyn is determined to continue to be an advocate for herself and help others advocate for their children. "My strength is what he mimics."

STACI DIROCCO | PELHAM, NH

Relationship to Duchenne: Mother

Staci is a single-mother to two boys with Duchenne muscular dystrophy. She is a licensed nursing assistant, learning the ins-and-outs of Duchenne. Recently, she has been a community ambassador for two years. She is looking forward to making connections with other parents and caregivers who have kids with Duchenne.

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ANTHONY DEVERGILLO | BEDMINSTER, NJ

Relationship to Duchenne: Individual affected by Duchenne

Anthony has done the most to stay optimistic and help other families while living with Duchenne muscular dystrophy. He is an advocate for inclusion, social connections, and accessibility for those that live with disabilities. Of all the Jett Foundation programs, Anthony enjoys Camp Promise the most: "I love Camp Promise and that it allows for people who live with Duchenne to take a break from their disease, try new things, make new friends, and have fun!" He is excited to continue to assist other Duchenne families with whatever they may need!

ASHLEY LESHURE | PENN YAN, NY

Relationship to Duchenne: Mother

Ashley is the mother of Carter and Chase, two boys who have Duchenne. She dove into the nursing field out of reaction to her boys' diagnosis, looking to find more answers and prepare for caretaking: "Obtaining my Bachelor of Science in Nursing has led me to becoming a fierce advocate for my boys. I teach all of the new school faculty about Duchenne each Fall," says Ashley. She believes being a Duchenne mom is very powerful within itself, and combining that with her nursing makes for the ultimate point person for her sons.

ROSALIE CALLAHAN | RONKONYOMA, NY

Relationship to Duchenne: Mother

Rosalie is a mom to two boys, Christopher (15) who was diagnosed with DMD, and Dominic (11). She has also been married to her husband Chris for 17 years. When she isn't spending time with her family, she is a pediatric Occupational Therapist (OT) working in a school, as well as in kids homes that are medically fragile and can not attend school. Rosalie has been a Community Ambassador for one year. She hopes to provide support emotionally and mentally to anyone that reaches out. Her favorite moment has been helping others learn about the Jett Giving Fund program. "Being able to offer hope in the midst of chaos is an amazing feeling," she says.

HEATHER FITZGERALD | EATON, OH

Relationship to Duchenne: Mother

Heather, her 11-year-old son Jase, and his father Aaron enjoy being outdoors, spending time together, and drag racing. Heather says "It would be an honor to represent Jett Foundation as a community ambassador and to reach out to families in need as a guide for comfort." Her favorite elements of the Duchenne and Jett Foundation communities are Rare Disease Day, World Duchenne Awareness Day, conferences, and Porch Nites.

YULAUNDA KISER | MONROE, OH

Relationship to Duchenne: Mother

Yulaunda is a mom to her 12-year-old son William who is diagnosed with Duchenne, and transitioning into a wheelchair full-time. Almost two years ago, Yulaunda took part in Jett Foundation's Accessible Vehicle Program and received a mobility van. "It has changed our lives tremendously," says Yulaunda. Now, Yulaunda has been a Community Ambassador for one year, assisting other families in their journey. She hopes to provide as much knowledge to families, while learning new information along the way. "It's a scary place to be, but we are stronger together." she says.

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TRACEY BRINKLEY | WAYNESBORO, PA

Relationship to Duchenne: Mother

Tracey is the mother of Ayden, a 7-year-old who was diagnosed with Duchenne in 2021. "I want to help raise funds and awareness for Duchenne," says Tracey. Tracey has connected with the Duchenne community through Jett Giving Fund, Porch Nites, and World Duchenne Awareness day. She says, "Porch Nite helped me know where to turn for more information and learn more about Duchenne." Tracey is studying to become a child advocate in schools. She wishes to help families navigate IEPs and 504 plans.

PERLITA HAINS | LEBANON, PA

Relationship to Duchenne: Mother

Perlita's youngest son, 16-year-old Levi, is diagnosed with Duchenne muscular dystrophy. Her family enjoys the annual Jett Ride, where Levi's two older brothers ride for him and bring awareness toward Duchenne muscular dystrophy. Perlita is a very active advocate and voice in the Duchenne community. Perlita helped create Porch Nite and always extends a helping hand to any family in need. "I feel that my knowledge of Duchenne and skills in public speaking are an asset as an ambassador," she says. "I am honored to help and will speak whenever I can about how supportive our community is."

EMBER THOMAS | CORRY, PA

Relationship to Duchenne: Mother

Ember is a mother to two sons with Duchenne muscular dystrophy. Her sons are 12 and 10 years old. Recently, Ember participated in Jett Foundation's Jett Giving Fund program to obtain safe and accessible transportation for her sons, Rugar and Wyatt. Now, as a Community Ambassador, Ember is hoping to help other parents navigate the journey of Duchenne. One of her favorite programs is Porch Nite because of the connections with other moms she has made. "There is a need to help parents navigate the journey of Duchenne, it is overwhelming when you get the diagnosis and there is very little emotional support to help the parents," she says.

CARRIE REYNOLDS-CLARK | JONESTOWN, PA

Relationship to Duchenne: Mother

Carrie has two sons with Duchenne aged 12 and 20. She says, "It has been a very tough road at times, but a road I would still choose to travel. We are tough moms!" Her family loves creating new experiences together and try to live each day to the fullest. "The support I have received from other Ambassadors made me want to be part of such an amazing organization," she says. "Great people do great things!"

JILLIAN MOORE | COLUMBIA, TN

Relationship to Duchenne: Mother

Jillian's son Aiden is 9-years-old and was diagnosed with DMD at the age of three. He is the light of her life and she puts being a mom first. She comes from a medical background but has put that on standby to care for Aiden. She is passionate about carrier issues and making sure moms get the care they need so they can be strong and healthy. Jillian has been an ambassador for 4 years. Some of her favorite memories of being involved with Jett Foundation are meeting other ambassadors, Porch Nite, attending the rare disease summit in Washington D.C., and meeting countless families along the way. She looks forward to continuing helping new families navigate through diagnosis and being able to share her family's clinical trial participation journey.

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SUSAN CALDWELL | WAXAHACHIE, TX

Relationship to Duchenne: Mother

In addition to single parenting her son who has Duchenne, Susan is active in her church and son's Boy Scouts community. Susan has also been a Community Ambassador for one year, and hopes to create more recognition around Jett Foundation's support for families. She says, "I would love to assist families in Texas who have questions about Jett Foundation's Accessible Vehicle Fund and Emergency Fund." She enjoys attending Porch Nites and educational conferences!

TAMMY CRAIN | FRANKSTON, TX

Relationship to Duchenne: Mother

Tammy has been part of the Duchenne community for 17 years. Her son, Tristan, was diagnosed with Duchenne muscular dystrophy at the age of two. "Even though our family has had its moments of mourning and rejoicing, we continue to learn how to best navigate this life. I feel our families have to jump through so many hoops to get any type of assistance, be it financial, physical, or emotional. Home modifications are a struggle, equipment and accessible vehicles are a struggle, travel is a struggle. I just want a newly diagnosed family to have all that information and access from day one!"

SOPHIA FLYNN | THE COLONY, TX

Relationship to Duchenne: Mother

Sophia is a single mother to her 16-year-old son who was diagnosed with Duchenne at 6 years old. Her life goal is to make sure that he is loved and supported through this life they didn't expect. She says, "Jett Foundation was one of the first places I started with through their Porch Nites and have really enjoyed the community. I feel that being an ambassador is something in that really suits me. I have always been someone who enjoys helping others and giving them the support they need. I look forward to connecting more to our Duchenne community and learning from all of you and being a support for those who need it."

TUSHAR TANGSALI | FLOWER MOUND, TX

Relationship to Duchenne: Father

Tushar's sons, Neil (12) and Neivaan (8), are diagnosed with ultra-rare mutations in the early part of the dystrophin gene. Tushar follows research diligently in all areas of Duchenne and enjoys connecting with other DMD families, as well as providing guidance on the different applicable trials and the nearest trial centers. Tushar attends all Duchenne conferences, pharmaceutical conventions, and FDA CBER sessions, and is trying to streamline the eligibility criteria for trials and the ensuing enrollment process to address the unmet needs of all segments of the DMD population.

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TERESA WOOD | HASLET, TX

Relationship to Duchenne: Mother

Teresa is the mother of three children and six stepchildren. Her youngest, Matthew (20), was diagnosed with Duchenne at the age of seven. "After diagnosis I spent the next couple of years breaking into tears when I thought about the disease," she says. "But slowly, with the help of other families and organizations, I was able to say Duchenne without tears and decided to begin raising funds and awareness for the disease. I, myself, am a carrier and I know how important it is to look after ourselves in addition to our children with Duchenne. I hope to be able use all of my experience to be a resource for the organization and for any families that might need my help.

MELISSA MCMILLAN | LAYTON, UT

Relationship to Duchenne: Mother

Melissa, also known as Missi, and her husband Sean have been married for 8 years and have three children together. Their oldest daughter is 7 years old and their second son is 5. Their youngest son (2) is diagnosed with Duchenne muscular dystrophy and loves to be right next to our his siblings, doing all the things they do. "The reason that I have a desire to be an ambassador is because ever since he was diagnosed, I have tried to reach out for support and it was hard to find in our local community. I am hoping that I am able to be that person that I was looking for," says Missi.

DJ KIMBLE | UPPER TRACT, WV

Relationship to Duchenne: Individual affected by Duchenne

On top of indulging in topics around history, nature, and politics, DJ finds the most joy in spending time with the great family he has. "My family sees me as me, and not as my disability," says DJ. At 42 years old, he feels he can be a great friend and mentor to others in the Duchenne community. "I have developed a lot of knowledge and life hacks that I would love to share with others from over 40 years of living with Duchenne!" he says. DJ loves the escape that Camp Promise provides and the friendships he has formed in the Duchenne community.