

## 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.

### **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.

### **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.

### **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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### **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."

### **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.

### **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.

### **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.

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### **PAUL & LAURA HEATON | WORDEN, MT**

**Relationship to Duchenne:** Parents

Paul and Laura are the proud parents of Elyse (11) and Grant (9). Grant was diagnosed with DMD at age 3 and they have been working ever since to spread awareness and raise money for research through fundraising. "When Grant was first diagnosed it was hard to find other families in the same situation as us and to get first hand information from. We are more than happy to visit with anyone anytime to give them a hand."

### **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."

### **LORI SAFFORD | PELHAM, NH**

**Relationship to Duchenne:** Mother

Lori is the mom to three adult children affected by Duchenne. Benjamin (28), Samuel (26) and Lydia (25) were all diagnosed in 2002. She and her husband Mike enjoyed 17 years of marriage before he passed in 2012. Lori has navigated building an accessible home, homeschool, private & public school, college, accessible driving, home health and mental health, Medicaid, Medicare, Social Security and palliative care. Lori's faith and dedication to Jesus has enabled her to walk this path with hope, peace and joy. She enjoys mentoring and advocating for other families with disabilities. She has a B.A. in Business Mgmt. & M.A. in Communication. Mgmt.

### **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.

### **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!

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### **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.

### **KIMBERLY ODELL | BEAVERCREEK, OR**

**Relationship to Duchenne:** Mother

Kimberly is a mother of 5, with a blended family. Her daughter, Mesa, was diagnosed with muscular dystrophy at three years old. Through a journey that involved testing at the National Institute of Health, Mesa was diagnosed with Duchenne at nine years old. Mesa also has cognitive impairments. Kimberly is passionate about supporting families going through the shock of a diagnosis. She is a Veterinarian by trade.

### **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.

### **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.

### **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."

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### **CARRIE REYNOLDS-CLARK | JONESTOWN, PA**

**Relationship to Duchenne:** Mother

Carrie's 13-year-old son lives with Duchenne. 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, was diagnosed with DMD at the age of three. He is the light of her life and she puts being a mom first. 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 5 years. Some of her favorite memories of being involved with Jett are meeting other ambassadors, Porch Nite, attending the rare disease summit in Washington D.C., and meeting 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.

### **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!

### **SOPHIA FLYNN | THE COLONY, TX**

**Relationship to Duchenne:** Mother

Sophia is a single mother to her 17-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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### **RACHEL LORANCE-JONES | MEADOWLAKES, TX**

**Relationship to Duchenne:** Mother

"Rae" is a mother of two boys. She owns and operates a restaurant in downtown Marble Falls, 45 minutes from Austin, TX. Their youngest son, Jace, was diagnosed with Duchenne in March of 2023 at the age 9. "Without the support of other DMD moms and organizations like Jett Foundation, I don't think we would be as far as we are in our healing process. This disease is a roller coaster of emotions and I want to help others like those who have helped me."

### **CICI NELSON | CLINTON, UT**

**Relationship to Duchenne:** Mother

Chris and Cici are the proud parents of Aj (12). Aj was diagnosed with DMD at age 3. "We found ourselves lost in the world of Duchenne. We were lost trying to navigate the diagnosis, doctors, and specialties. It felt like a long and lonely journey. Our goals as ambassadors are to help families navigate the disease and all components that come with it. We want to build a community in our area where we can get together to learn, support, and simply have fun. We want to help the community navigate and advocate for all areas that come with DMD. We know it can be a scary and long journey, but with the right support, we can get through anything together."

### **JADA BAFAS | SPOKANE, WA**

**Relationship to Duchenne:** Individual affected by Duchenne

Jada is a mother to Mason (5) and Jack (2). Mason and Jack were diagnosed with Duchenne in the spring of 2023. Jada decided to leave her career to become a full-time caregiver and advocate for Duchenne. As a family, they started a YouTube channel (The Bafus Family) to give hope, document their medical journey, and to shine light on Duchenne for the community. "This disease can feel very isolating at first, so when we decided to start our YouTube channel, it has been an amazing outlet to connect with other families. I am thrilled to continue to spread awareness with Jett Foundation!"

### **DJ KIMBLE | UPPER TRACT, WV**

**Relationship to Duchenne:** Mother

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.