



2021 MSRGN Genetic Navigator Directory

Arizona: Noan Dublinski



Noan Dublinski has been working in Arizona with children who are deaf/hard of hearing for over 25 years as a teacher, audiologist, and currently as an early intervention provider. Noan has her Master's degree in Audiology and her Bachelor's Degree in Deaf Education. Noan's youngest daughter was diagnosed in infancy with cystic fibrosis, a progressive genetic disease. Noan's work and life experience have fueled her desire to support families in accessing genetic information and in advocating for those children receiving genetic diagnoses.

Email: arizonagenetic@gmail.com

Colorado: Jamie Stefanski



Jamie Stefanski is a Physical Therapist and ABM NeuroMovement Practitioner, a mother of two children with the rare genetic disorder TELO2/You-Hoover-Fong Syndrome and has been part of the Mountain States Regional Genetics Network (MSRGN) Colorado State team since 2018. She is also on the Special Education Advisory Committee (SEAC) for her local school district and has hosted multiple MSRGN Genetic Pop-Ups, free NeuroMovement clinics, and other special needs events. Jamie and her family have lived in Colorado since 2017 as well as 5 other states previously, so she has experience navigating the medical system, insurance system, special needs, medically complex and genetics worlds as a professional and parent. She looks forward to helping families as a genetics navigator.

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Montana: Jennifer Banna



Jenn Banna's family lives in Montana where she directs Montana's Family to Family Health Information Center. Genetics became a large part of her life when her daughter was diagnosed with PittHopkins Syndrome in 2012. She has been involved with MSRGN as a genetic ambassador, genetic popup presenter and a Montana team co-load.

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Nevada: Hannah M. T. Barnhart



Hannah M. T. Barnhart has a Bachelors degree in Health Care Administration and an Associates in Medical Assisting. For about 6 years, she was a part of the only Pediatric Genetics Clinic in Alaska working alongside a team of Geneticists and Genetic Counselors from Washington and Oregon. Currently, she is one of the Co-Leads in the Nevada State Team with MSRGN.

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New Mexico: Jennifer Bartz



Jennifer Bartz has a BA in Psychology, and her meaningful experience comes from having a child (James) with Down syndrome and some other rare disorders. James died in December 2018, and Jennifer continues to be involved advocating for families and children in New Mexico and Nationally. Volunteer positions that connect her with resources for families with a child with genetic conditions:

[Family Advocate Board Member](#)

Founder and President: [Heros Path Palliative Care](#)

[Medically Fragile Family Advisory Board Designee](#)

[Family Advocate](#) NMDOH

[Family Advocate](#) MSRGN

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Texas: Lourdes Torres



Lourdes Torres is the proud mother of 3 beautiful girls and has been married for over 20 years. She has a career as a computer systems engineer, which she practiced for several years until the arrival of her third daughter, who, when born with an ultra-rare genetic condition (HNRNPH2 mutation), caused a 180-degree turn in her family and professional life. She is currently a parent educator for the Children's Disabilities Information Coalition-Community Parent Resource Center where she happily engages in informing and training other parents in the difficult process of raising a child with a disability, helping them to be effective advocates and provide a better future for their children. She likes to spend time with her family cooking and traveling at any opportunity; she loves to paint pottery and create foil art.

Spanish:

Lourdes Torres es orgullosa madre de 3 hermosas niñas y está casada desde hace más de 20 años. Tiene una carrera en ingeniería en Sistemas Computacionales, misma que ejerció por varios años hasta la llegada de su tercera hija, la cual al nacer con una condición genética ultra rara (mutación HNRNPH2), ocasionó un giro de 180 grados a su vida familiar y profesional. Actualmente es educadora de padres para la Coalición de Información sobre Discapacidades de los Niños donde se dedica felizmente a informar y entrenar a otros padres en el difícil proceso de criar a un hijo con discapacidad, ayudándoles a ser defensores eficaces y brindarles un mejor futuro a sus hijos. Le gusta pasar tiempo en familia cocinando y viajando en cualquier oportunidad; le encanta pintar cerámica y crear arte en aluminio (foil art).

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Utah: Tristan West



Before Tristin West was the mother of Jayson (9) and Cozette (4), she was focused on big career dreams and collecting college degrees (2 master's in Language and Teaching). Her dreams changed when her son Jayson was born (2011), but her acquired determination, persistence and research skills were helpful when navigating Jayson's rare, complex health conditions, several brain and cranial surgeries, medications and many therapies. Jayson's genetic diagnosis was labeled "unknown" for years due to the many barriers that keep patients from getting answers; but with the help of Tristin's research, connections, resources, determination and a whole lot of patience, Jayson got a diagnosis--MCTT Syndrome (MN1 C-terminal Truncation). Tristin loves to help families tell their stories, overcome barriers, know their resources, make connections and recognize what is in their control as they navigate their own diagnostic journey.

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Wyoming: Melody Ruppel



Melody Ruppel stepped into rare disease and genetic advocacy following the genetic diagnosis of her second born. Being a wife and mother of 4 youngsters, daily life is now intertwined with educating those who surround them in their beautiful community of Lander, Wyoming. With a background in teaching, her love for learning has spurred her to educate herself in the importance and impact of Newborn Screening, early intervention and access to appropriate medical care. She has also been actively engaged in organizations such as the National MPS Society, National Organization for Rare Disorders, and now MSRGN. She hopes her role as Genetic Navigator will provide her with the tools to better support and encourage other families impacted by genetic conditions in the state of Wyoming.

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Genetic Navigator & MSRGN Projects Manager: Kristi Wees



Kristi Wees comes to Mountain States Regional Genetics Network as a parent advocate. She brings previous experience working in a laboratory and research setting as a chemist as well as scientific sales and marketing experience after completing her master's degree in chemistry from UCLA. Kristi has utilized social media in the last 8 years as she had focused on outreach, support and encouragement to mothers, especially mothers of children with special health care needs. Kristi's daughter was suspected of a genetic condition when she was young. She helps other families navigate the medical system through her patient advocacy work at www.EmpoweredAdvocacy.com. Kristi is also a national advocate for family-centered telehealth with National Family Voices. She is also as a consultant with the National Genetics Education Family Support Center.

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