



## 2022 Caregiver of the Year

Nobody would blame Betty Vertin if she reserved her time, energy, faith, and voice for herself, her husband, and their 7 children. With children ranging in age from one to twenty-one, Betty and her husband Jason fill their days with work, baseball games, team tryouts, track and field meets, theatre tryouts, rehearsals, performances, filling out first job applications, studying for driver's license tests, drop-offs, pick-ups, playdates, church, and – undoubtedly – more.

But Betty and her family also make time for things like hydrotherapy, physical therapy, cough assist machine time, wheelchair maintenance, construction projects to make the house wheelchair accessible, construction projects to add a lift track, MRIs, pulmonology appointments, neuromuscular tests, cardiologist visits, blood work, medication adjustments, IEP meetings, and – undoubtedly – more.

Betty is wife to Jason and mom to Lexi, Max, Chance, Rowen, Charlie, Mary, and Callie. Max, Rowen and Charlie live with Duchenne Muscular Dystrophy, or DMD. Phrased perhaps even more honestly - in ways visible and invisible – the entire Vertin family lives with DMD. The discovery of the diagnosis for all three boys occurred within the span of just one year – between July 2010 and August 2011. Every moment of every day since then has been affected by the diagnosis.

Though perhaps not her intention in the hours and days that followed the DMD diagnosis, Betty has become a beacon of hope, authenticity, and advocacy for DMD families around the world through her blog and advocacy work. Her raw honesty about her family's journey with DMD is usually eye-opening, at times heartbreaking, and always relentlessly hopeful. Betty holds nothing back when she writes or shares her family's story with others. She shares her sadness, her fears, her moments of anxiety, and her struggles. She shares her faith, her joys, her gratitude, her perspective. And she shares the family's triumphs - grand and small – to signal to the DMD community that such moments can and do exist beyond the darkness of such a diagnosis. Those triumphs are usually disguised as beautiful simplicity:

- one son's first job
- another son's cooking and dancing in the kitchen with mom
- canon ball splashes by another son
- getting everybody to school or church on time
- the entire family getting to ski in Colorado

Betty always finds time to share her energy, her faith, and her voice with the DMD community. Betty's approach to navigating a life lived with DMD is done with equal parts grit and grace. By sharing their experiences, the Vertins bring light to hundreds of other mothers, fathers, siblings, and caregivers struggling with – or celebrating – the same things. Max and Rowen and Charlie and their needs are at the center of everything Betty and her



## 2022 Caregiver of the Year

family do. Through her blog and work with DMD groups, Betty offers the world a chance to witness the beauty behind the chaos that comes with a devastating diagnosis like DMD. The lessons Betty has learned, she has shared with the entire DMD community. Betty teaches others that life with DMD will be scary, and hard, and messy, and surprising, and happy, and blessed and beautiful and – undoubtedly, most certainly – so much more.

Betty started her own blog, Weathered Storms ([weathered-storms.com](http://weathered-storms.com)), in 2016. In 2021, she started blogging full time for Muscular Dystrophy News Today. She was encouraged by family and asked by fellow DMD families and caregivers to share her experiences.

Since then, she has shared her story across numerous platforms and with numerous groups to raise awareness build a community with her fellow DMD families:

Betty's work/interviews to advocate for DMD therapy advancement/drug approval and review: <https://people.com/human-interest/brothers-with-rare-form-of-muscular-dystrophy-can-no-longer-take-drug-that-was-improving-their-lives/>

<https://www.newsweek.com/muscular-dystrophy-heartbroken-family-awaits-fda-decision-experimental-drug-681835>

Article with JETT Foundation: <https://www.jettfoundation.org/blog/2021/4/6/jett-foundation-gifts-nebraska-family-accessible-van>

CHAD Nebraska Story: <https://www.chadnebraska.org/vertin-familys-story>

Betty's Personal Blog before Muscular Dystrophy News Today: <https://weathered-storms.com/>

Betty's Blog with Muscular Dystrophy News Today: <https://musculardystrophynews.com/category/columns/party-of-9-a-column-by-betty-vertin/>