

Chapter 17

DMDD from the Front Line: The Parent's Perspective

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The parents quoted in this chapter have willingly shared their children's stories, to further educate the medical community about disruptive mood dysregulation disorder (DMDD). Residing in different parts of the United States and as far away as the United Kingdom, their unique stories strike a similar chord. These parents have been on the front line since day one and give a candid account of their child's development. Pooling their information has allowed for observations to be made that are highlighted in this chapter. The children profiled have all exhibited irritability, anger, rage, and low frustration tolerance. In addition, some also have shown impulsive behaviors, sensory issues, anxiety, depression, and suicidal ideation. Through these vulnerable stories, these parents provide a glimpse into the exhausting maze they have encountered while seeking a diagnosis. Dealing with various medications and harsh side effects as they inch closer to a possible solution has become part of daily life. Due to a lack of resources on DMDD, and no standard of care treatment, these parents have been both caregivers and researchers, all while living in a chronic state of chaos. Despite a parent's best efforts, emergency room visits and

hospitalizations, multiple times for many, are sadly the norm for children and adolescents inflicted with DMDD.

Another heartache for parents is dealing with an educational system that does not understand their dysregulated child. Further, many of these families have encountered the police numerous times, and some have dealt with Children and Protective Services, due to their child's escalated anger. DMDD is not an illness that affects only the child. The reality is that this disorder encompasses the entire family in its grip and brings about shame, judgment, isolation, and trauma. Keeping a marriage and family intact is an extreme challenge while living with a child who is like a living time bomb, never knowing when they will explode.

Through their tumultuous journeys, these parents have each acquired an education that is valuable to the medical community. The vast wealth of knowledge and wisdom they have gained has been hard-earned, often accompanied by physical assaults, bruises, and layers of deep emotional trauma from the one they love the most — their child. The perseverance, tenacity, and sheer will to help their mentally ill child, while they often suffer in silence, is a testament to their love. Hopefully, through their raw accounts where they expose it all, a better understanding of, and treatment for, DMDD, can finally emerge.

The Early Years - *Birth through Preschool*

The parents in this section openly share what their children were like as infants, up until the start of preschool. It's important to note that these stories include everything from biological to adopted children, uneventful to complicated pregnancies, normal to traumatic births, single delivery to twins, predisposed genetic history, and early childhood trauma. Some parents have

noticed their newborns being fussy, irritable, and difficult to soothe. By contrast, other parents remembered happy, easy babies who didn't exhibit chronic irritability until they reached their toddler years, or even just prior to attending school. No matter how these children entered the world, DMDD doesn't seem to discriminate.

Jonas (age 13): Jonas' mother shares, "My son should have been a healthy, happy child. I had a full-term, uncomplicated pregnancy and birth. He was being raised in a stable home with two parents who not only loved him very much, but also each other. I was able to stay at home with him. We rarely watched television. I cooked from scratch, even making my own baby food for him. As an infant, there were no obvious red flags. As he matured, he did seem to have very little tolerance for frustration. I spent much of his first year telling myself, 'He'll be happier when he can sit up, crawl, etc.'. He never was. Within a few months after his first birthday, the anger began to flare up. Jonas would get angry with me often, and when he did, he wanted to hurt me. He would pinch me, pull my hair, and bite me."

Nathan (age 8): Nathan's dad recalls, "My son had always seemed uncomfortable. As early as a few weeks old, we noticed Nathan would writhe around, and could not be soothed by anyone or anything. Cradling him always felt like holding a cat that didn't want to be picked up. The only time he seemed at peace was when he was asleep. We also noticed some other unusual behaviors. He was extremely hypersensitive to touch. He would engage in dangerous play and didn't seem to notice that he had been injured, and often showed confusion when he hurt others."

Patrick (age 12): "We adopted Patrick at two weeks old," says his mother. "He was our first child. From the beginning, we noticed quirks but were reassured by family and friends it was

all normal. Patrick wouldn't sleep unless swaddled very tightly, even after he started rolling. He required a room completely pitch black – any light would leave him awake for hours.”

Barry (age 17): Barry's mother shares, “We adopted Barry, as a drug-exposed infant. There were struggles early on, mostly with getting him to sleep. I don't remember when the rages started, but I do remember using a tactic I learned from a foster parenting class to take him down to the floor and restrain him to keep him from hurting himself or me.”

Ben (age 16): “Ben was an easy baby,” says his mother. “He was quiet and went along with the flow for the first few years. When he was three, his biological father and grandmother abused him and locked him in his room for days. I was attending a family event out of state, and when I returned, Ben was different. The happiness in him was gone, and his behavior changed drastically. When reprimanded, he would hide, not speaking to anyone, not looking around. He became very attached to me, wanting to be near me all the time. My children and I moved a few months after the abuse incident.”

Bella and Lizzie (identical twin girls, ages 16): Bella and Lizzie's mom explains, “My pregnancy was difficult and stressful, as it was unexpected, and I was already at an unhealthy weight of over 300 pounds. I was caring for four children (ages 12, 9, 4 and a 9-month-old baby), plus working 30 hours a week at home during the night. Otherwise, though, the pregnancy was a relatively uneventful, mono-di, twin pregnancy. The girls were delivered via c-section at 36 weeks, weighing in at 6 lbs. 8 oz. and 7 lbs. 8 oz. They stayed in the NICU for a few days following their birth, due to some jaundice and low blood sugar, but following that, they were doing well, and we were all excited to get them home and join our family.”

Jordan (age 12): “Jordan is my fifth-born child out of seven,” says his mother. “We knew from an early age that there was something wired differently for Jordan. As a baby, he was easily overstimulated, hard to calm, and just consistently unsettled, needing something. I had experienced a blood clot early in the pregnancy, and we weren't sure if I would miscarry. The blood clot was larger than the baby until about the 14th week. Also, I found out I was pregnant while my mom was in Intensive Care, following a near-fatal car accident. I believe the stress and trauma of that incident impacted him while he was in utero. So many things are forming in the brain during this time, and I can't help but imagine that it impacted his development.”

Zack (age 16) and Annie (age 14): “Our family has no history of trauma, but my father has bipolar disorder,” says the mother of Zack and Annie. “Both of my pregnancies were full-term and healthy. Zack was 9 pounds, and Annie was 8 pounds. I breast fed, had healthy nutrition, all of it. I did have a long pushing session with Zack, and at first, he was not breathing. His first Apgar score was low, but the second was immediately normal. He was on a fetal monitor the whole time. My daughter had a very normal, uneventful birth. They were both vaginal births.

Zack was fussy at times and had a very difficult time getting to sleep. Annie had a hard time with separation, but it may have been just a phase.”

Kellan (age 12): “Kellan was difficult to soothe and settle as a baby,” his mother recalls. “The older he got, the more irritable he got. There would be short periods of fun and laughter, but he was sad and irritable most of the time. He was also visibly irritated with his clothes, socks and shoes, as well as sounds. The usual look on his face was upset or angry, and it showed in photos. He stopped napping altogether by 12 months old, which caused problems for his daycare provider. By 18 months old, this provider told me that she thought he had ADHD. Early on, his

behavior concerned me, as I had grown up with a very violent brother who had been diagnosed with “ADHD with aggression” in the early ‘90s. My brother caused a lot of physical and emotional trauma for our entire family. I was afraid my son was going to have the same problems that my brother did. My father also had been diagnosed with manic depression (later changed to bipolar 1) and I was concerned that my son could be genetically predisposed to that as well.”

Once these children learned to say their first words and meet milestones, frequent and intense meltdowns, as well as severe anger, raised red flags for parents who had already experienced fussy infants. To those whose babies were relatively easy, new behaviors started to present in their now-toddlers.

Bella and Lizzie: “I fondly recall that first year with our twins as quite special. Bella and Lizzie were incredibly sweet, and everyone loved them. Having the experience of watching all the milestones that babies reach, but in duplicate, was kind of magical. Once the girls began to get more mobile, around a year of age, things began to get progressively more complicated and difficult. Unlike their older siblings, they were quite shy and didn’t really warm up to people at church, or with extended family members.”

Nathan: “In these early years, we had to come to terms with the level of destruction Nathan’s behavior would bring to our home. Sometimes he would break things by accident. Other times it would seem deliberate, and often out of frustration.”

Patrick: “He had an amazing vocabulary from an early age, and a weird obsession with grotesque things. Patrick easily manipulated others to get what he wanted. He threw hours-long tantrums over random things, didn’t respond to traditional discipline, and insulted us with words like “eat poop” when he was angry. In the church nursery, he would scream the entire time.

When I would hold another child, he would bite, scratch, and hit me until I put the child down.”

Jonas: “Throw shoes, Mama’s face!” was my son’s first sentence. “He was not yet two and chronic irritability and rage had become the norm in our lives. By the time he was two, he was adding verbal attacks to the physical ones. He would have these angry rages that would last for a long time, often close to an hour. It was as if he had this pent-up rage that just needed to get out. This happened almost every day of the week, often multiple times a day. When Jonas wasn’t raging, it felt like we had a good relationship. He liked to snuggle and would rub my hair on his face to comfort himself when falling asleep. We would hold hands and go on walks. He would help me cook, clean, and care for our dogs. We would spend hours each week reading books.”

As these toddlers started transitioning from home to preschool, most of these parents noticed their children’s frequent meltdowns and moments of destruction happening there too. On the contrary, other parents received nothing but positive reports from their children’s preschools, saving their dramatic behavior for when they got home. However, as some of these children got older, that changed for them, and school morphed into a place for meltdowns, rages, and chaos for them as well.

Nathan: “Around age three, Nathan started going to the nursery school. At first, they told us they were only willing to accept him for two hours per day, but after about a week, they told us they were unwilling for him to attend at all. The nursery stated that Nathan would frequently jump up onto tables, put his hands in the paint and smear it everywhere, and would get angry and violent when an adult would try to stop him.”

Patrick: “Patrick’s behaviors followed him into three preschools, two of which we were asked to leave. He didn’t follow the rules, refused to do any work that frustrated him, and would mock and physically hurt the other students. The second preschool suggested exorcism, after he drew a picture of 16 drops of blood falling from a knife. At the third preschool, he spent most of his days at home, after acting up in class. The classroom assistant quit out of frustration. Patrick did not respond to discipline in any form at home or at school, but he knew how to do just enough to get by, and he could charm people with his extensive vocabulary and quick wit.”

Bella and Lizzie: “I remember the first time we really started thinking that something was different for Bella and Lizzie, was when we started talking to them about going to kindergarten. They hadn’t attended preschool, which meant that kindergarten would be their first experience with school. Every time we talked to them about it, they would become unhinged, screaming and crying and saying that they didn’t want to go.”

Ben: “I had Ben evaluated at four years old, and he was placed in a special education preschool program. He wasn’t disruptive, but he would withdraw within himself when faced with a stressor. In kindergarten, his teacher was thrilled to report that he needed to be reminded to not talk to his classmates during class, as he was finally being social. First and second grades were the same way: he was quiet, didn’t volunteer for tasks, or answer questions. Third grade started his downward spiral at school.”

Jonas: “By the time Jonas was three and a half years old, I had been bitten by him countless times, butted in the face, kicked, punched, had my hair pulled, scratched, had things thrown at me, and endured the verbal assault of a sheltered toddler. Jonas’ rage also happened with dad and grandparents – people he knew well and trusted. With others, he was always a

model child. At church, I would hear of how sweet and precocious he was. There was never a bad word from the preschool he attended two days a week. There was a period of time around Jonas' fourth birthday, where his rages seemed to be fewer than the past several years. During this time, we chose to get pregnant with our second child. By the third trimester of my pregnancy, the rages had returned full force, and Jonas had started defecating in his bedroom during time out, in addition to urinating. I learned to shield my belly from his physical attacks."

Zack: "My son had developmental delays in his gross motor skills, although he eventually caught up quickly, and then oddly, would end up ahead. For example, he couldn't ride a tricycle until the age of four, but then just hopped on one day and rode by himself. He was always cognitively advanced but did exhibit aggression with other kids in preschool."

Jordan: "As a preschool child, he was quite precocious and active. He got in a lot of trouble, as he was consistently not listening and was being told to stop doing things. Repeated offenses landed him in the office often. He started school already reading, but I knew that there was something underlying some of this behavior that appeared to be defiant, intense, or difficult to understand. He hardly ever stayed in bed at night."

DMDD Outbursts – *What they're really like*

One of the most difficult symptoms of DMDD is the persistent outbursts that parents often describe as fight-or-flight rages. In these instances, children seem to be triggered by the slightest stimuli, or the smallest disappointment or embarrassment. Many parents refer to the outbursts occurring as if "a switch was flipped" because they happen so fast. It is emotionally and physically exhausting for a parent to manage their child during a rage, trying to protect them

from harming themselves and the rest of the family. Homes and possessions are broken and damaged. Many parents report that these outburst behaviors go beyond that of what is experienced with their neurotypical children on their worst day. The severity of the violence and destruction, as well as the duration of these outbursts, are demonstrated in the following accounts by parents who have witnessed them. For a DMDD child in crisis, whoever or whatever is in the way may be seen as a threat and may also be the target of verbal and physical attacks. The outbursts can be so intense that one would think these kids are fighting for their lives. Sadly, this is what their hyper stimulated brains think they are doing. When the outbursts subside, parents report their children are so exhausted, they have literally no energy left. Parents report it is common for their DMDD child to not even remember they had an outburst at all and may even argue about whether or not it actually occurred.

Carson (age 9): His mother said, “He received his first suspension in kindergarten, for gut-punching a female student who did nothing to provoke him. Restraining him made things worse. He would cry and scream and knock over furniture and throw chairs. The rages would last at least an hour. The more we tried to stop him, to calm him down, the worse he would get. He had almost no patience and would yell often. He broke his own glasses and destroyed beloved toys. He would yell things like, ‘I hate you! Why don’t you go be with your mom?’ (who is deceased) or ‘I want a new family. Idiot!’ When he came out of a rage, he wanted to cuddle and play, and we were still shell-shocked. It was like Dr. Jekyll and Mr. Hyde.”

Ben: “Ben started being violent at home at age six. He would push and hit, screaming as he lashed out. He would become extremely agitated if he was told, ‘No.’ He continued to get more violent and stronger as he got older. He would lash out at anyone that came around him.

He targeted his younger brother, hitting him with no provocation. At school, he started becoming violent by throwing chairs, supplies, hiding under his desk and lashing out at his peers and staff. He was removed forcibly from the classroom on multiple occasions. He was physically restrained by various staff, including myself, during these episodes. My mother told me he looked possessed when he was having an outburst, and that I needed to have him exorcized. I begged my family to understand that he wasn't intentionally doing anything. I tried for years to make them see that it was like a switch flipping inside of him, and he would lose control."

Eileen (age 15): The mother of Eileen recalls, "When she would get out of control, I would take her into a spare room, close the door, sit down, and hold her tight as she wrapped herself around me and beat her fists on my back. I figured it was better she beat on me rather than beat someone else or break something. I didn't know what else to do. She was violent and abusive towards her brother as well, and I wanted to keep him safe. That became unworkable as the punches became so hard, I would lose my breath. There would sometimes be bruises. The violence later escalated. She began breaking electronics, punching holes in the wall of our rental home, causing bruises and bumps, and hitting fellow students at school. We never knew what would set her off. A reprimand, teasing from her brother, a wayward clothing seam, unapproved meal choice. We walked on eggshells every day."

Barry: "He was cranky all the time and nothing could soothe him. But worst of all were the rages when the littlest thing would set him off. His eyes would get red, he would huff and puff, he would break things and get right up into our faces, curse and yell and scream and threaten. It was like being in an abusive relationship, where you walk on eggshells, hold your

breath and try everything you can think of to fend off the next incident. And when your child is a very dark-skinned, black male who weighs 230 lbs., you fear for his safety, as well as your own.”

Bella and Lizzie: “We had holes punched in walls all over our home, doors that had profanity carved into them, doors off the hinges, mirrors that had been smashed so that they could be used for self-harm because knives were hidden, and paint peeled off the walls. Lizzie would break things around the house, empty out our pantry and fridge items all over the kitchen floor, spill gallons of milk, and the list goes on. For Lizzie, the impetus was often boredom. Whenever she started saying she was bored, which would eventually turn into a chant, ‘I’m bored. I’m bored. What can I do? I’m bored’, we knew that it was time to batten down the hatches. When Bella got angry or frustrated, she would sometimes bang her forehead against the cement floor of our basement, enough that it would make her bleed. These were some of the most frustrating, petrifying, and heartbreaking experiences to witness, and we felt so helpless – we were at a complete loss.

Zack: “Our son was only 11 at that time. We had to restrain him frequently, because he would follow us and attack when raging. The rages could be triggered by something small or big, and his eyes would dilate large until he didn’t look like himself anymore. He was very strong during rages. Half the time, he could not remember what he said and did afterward. There was absolutely no processing with him, as he could not be reasoned with or make any choices in that state of mind. All we could do was remove his sister and try to keep everyone safe until the rage passed. My husband received a mild concussion from one incident during an outburst. The rage was severe, and he attempted to transport Zack to the hospital without an ambulance. While

transporting him, my son was seated in the backseat. He kicked my husband in the back of the head multiple times before arriving.”

Jeffrey (age 11): The mother of Jeffrey worked at her son’s school and was frequently called to assist when he would have an outburst in class. “He flipped over the resource teacher’s work desk, tore up his assignments, fled the classroom and yelled in the stairwells. He kept yelling, “I’m not an idiot.” He was in a far corner underneath the stairs. I got down on my hands and knees to get to him. I called for him, “It’s me, Mommy” and he responded, “Go away, Stupid!” He started swinging at me, and I held his hands as he screamed louder and louder. I looked in his eyes and he didn’t even look like my son while in this rage.”

Nathan: “There’s nothing like loving a kid who goes into uncontrollable rages at a moment’s notice. When he’s not physically violent, he’s so uncomfortable because of what is going on in part of his brain, and so lacking in any kind of filter, that you can hardly believe what is coming out of his mouth. It’s so profane and mean. During an outburst or rage, destruction is taken out on the home. Holes are punched in walls, glass broken, electronics smashed and destroyed. Many times, children break their own possessions in the process.”

Cid (age 15): Cid’s mother recalls how easily her son would be triggered. “I suggested we play a board game instead of watching a movie on a school night. This suggestion resulted in him stabbing everything in the garage with scissors.”

Patrick: “When the rages were over, Patrick would sob apologetically. It was hard to know if it was sincere or manipulative. Sometimes, we wondered if he even realized he had raged at all – it was as though he had blacked out. He would deny having raged and accuse us of lying about

him. When we would record a rage and show him, he would accuse us of hiring an actor and making the whole thing up!”

Lila (age 10): Her mother shares, “Before she was (somewhat) stabilized on medication, our daughter would have multiple rages a week. Sometimes she would have two or three in one day. They happened everywhere: at school, at home, and out in the world. Her rages are instant, impulsive, and impossible to control once they've started. Sometimes she yells things that don't make any sense like, ‘You all want to kill me,’ or ‘You all hate me.’ No one really knows what to do in those moments. Talking doesn't work; she'll only argue back and get more upset. She won't try any calming strategies, and she's too big to physically move anywhere. Once she's done, she is perfectly calm, says she's sorry, and can explain what went wrong and how she should have acted instead. But those of us who have witnessed it are scared and exhausted long after it's over.”

Parents of DMDD children and adolescents observe that these outbursts and behaviors take place in more than one environment, such as home and school or at home and in public. For most of the parent respondents, they occurred anywhere and anytime for their children.

Ben: “He became more violent and unpredictable, lashing out for no discernable reason. I was called into the school multiple times each week, either to intervene or bring him home. During one incident, his teacher attempted to force him into the locking room, and Ben fought intensely. His teacher, while restraining him, tripped over something on the floor and fell, dropping Ben as he went down. Ben was rushed to the emergency room with a broken arm. I was bitten and bruised and completely at a loss for what to do.”

Nathan: “While leaving drama club, he began punching me in the head, and leaning so much I thought I would fall over or drop him. The owner helped me carry Nathan’s stuff, and we got him in the car. On the way home, he was still in distress, trying to unlock the car door, taking off his seat belt, and still punching me in the head.”

Kellan: “When Kellan was five, we were out of town and had a flat tire. We were exhausted and waiting for over an hour in a supercenter, with nothing to stimulate Kellan or keep him occupied. He asked for a toy, and I told him, ‘No,’ and he started to rage and scream and slam the shopping cart seat (that collapses) over and over and over again, hitting himself in the forehead. His screams sounded like I was beating him, from the looks of the fellow shoppers staring at us. It took all the energy I had to keep him from getting out of the cart and running out of the store, into the busy parking lot.”

Parents of children with DMDD refer to an outburst as a fight-or-flight response because many times, they not only fight, but will elope. When this happens, children put themselves in harm’s way in the process, completely blinded by the obvious dangers that surround them. During these crisis episodes, parents are found either actively restraining their child from causing physical harm or trying to keep them from eloping and putting themselves in danger.

Eileen: “One night, when she was 11, she was so angry and fled our neighborhood, located not far from a major thoroughfare. She ran and I couldn’t catch her. I went driving around in search of her and a figure darted in front of my car. I almost hit my child! I was hysterical at the very thought. She fell into a sobbing mess once we got home. During another fight-or-flight outburst, she was pummeling me so hard, she severely injured my jaw, and the violence I endured

caused me to have a seizure. She then ran away, and we couldn't catch her, but she was home in about 30 minutes."

Bella and Lizzie: "Lizzy threatened to jump out of our car as we rode down the highway on multiple occasions. A couple of times, I ended up pulling over because I was so petrified that she was going to do it. On one of these occasions, the girls had their one and only friend in the car with them, who witnessed Lizzie jumping out of the car and running off into some bushes."

Kellan: "At the age of 6, Kellan was upset that I had left the house to go to the gym, leaving him with my mother. He got out the front door and started running away from the house and his grandmother. She was unable to catch him on foot and went back home to get the car to search for him. Within only 10-15 minutes, he was found nearly a quarter mile from home on a busy four lane, and the police were called. In kindergarten, Kellan was successful at eloping from school on at least six or seven occasions, and many more attempts were thwarted."

Carson: "He would take off walking down our busy street. On one occasion, he rode his dirt bike with nothing on but pajama pants, down a 55-mph road. When he came close enough to the house, I grabbed the handlebars and caused him to wipe out in our driveway. He told everyone I pushed him off his bike."

Jordan: "On one occasion, we were attending a doctor's visit. He had extreme anxiety about it. He just erupted with emotion as we pulled into the parking lot. He tried to lock me out of the car. I was alone and had to physically pull him from the car. I was afraid he was going to make a run for it. I had to hold on to him as we walked in, and proposed that from that point on, we would be using valet parking for his safety. Once, he left the school building, so the teachers were very leery of letting him go for walks to calm down, as they feared he might run."

Cid: “Cid was always prone to run, even as a toddler — in a department store, at the park, everywhere. It was challenging when he was little, but as he got older, his DMDD fight-or-flight episodes were nearly impossible. Cid usually managed to escape when we were in the car. His goal was to jump from the moving vehicle, to avoid going to school or the store or marching band practice or the gym. It should be noted that he *asked* to sign up for the marching band and the gym, so they were places that he should have wanted to go. He would even slam the car in park while the car was in motion, to try and jump from the car.

Finding a Diagnosis - *Comorbidities and Medications*

Finding a diagnosis for an irritable and explosive child, many of whom also show signs of impulsiveness, sensory issues, anxiety, depression, and suicidal ideation, is a long and arduous road, as parents reveal in the following section. Often, the first diagnosis leads to comorbid disorders that pile on, adding numerous acronyms labeling their youngster. Several parents cited exploring alternative and non-invasive therapies to curb behavior, before resorting to medication. With each new diagnosis, and in some cases misdiagnosis, came a new medication to try, that either worked for a short duration, exacerbated the behavior, or gave harsh side effects. Due to conflicting diagnoses, one parent went so far as to purchase a copy of the DSM-5. Another parent earned her degree in Sociology and Psychology, in the hopes of trying to figure out what was driving her son’s behavior.

As months turn into years, parents get desperate, as they continue to hit roadblocks and dead ends, and as they run out of treatment options. They begin to question whether there is hope for their mentally ill child. Oftentimes, multiple professionals are unsuccessful with

treatment plans, and parents sometimes begin relying on their own instincts and research skills, as they search the internet and online support groups for answers.

Ben: “Ben started seeing a psychologist when he was six. Due to the history of abuse, he was given the diagnoses of ADHD and PTSD, and the doctor started talking about medications. Instead, I attempted every dietary change I could find that might possibly help his behavior, removing things like artificial dyes, sugars, dairy, and so much more. I supplemented his diet with vitamins, with the hope that something would help. Nothing did, and I finally agreed to start medications. This was the beginning of years of medication trials and failures. Some would help a little, some not at all. Many made him gain weight, have sleep disturbances and he would say his head felt ‘mushy’. Over the years, he was prescribed dozens of medications, including: Invega, Abilify, risperidone, Ritalin, Adderall, Vyvanse, Strattera, clonidine, guanfacine ER, Wellbutrin, olanzapine, lithium, divalproex, citalopram, fluoxetine, sertraline, and many others. He was often on several medications at a time, trying to find the right combination.

During the years that he was medicated but unstable, we were passed from clinic to clinic, with doctors telling me that there was nothing they could do for him, because nothing they tried really helped. He went through a battery of testing at age eight, resulting again in the diagnoses of PTSD and ADHD, and adding anxiety. He was hospitalized on three occasions, but was discharged just as unstable as he went in. When he was 10, he went through yet another battery of tests, and was diagnosed with DMDD, ADHD, PTSD, GAD, and depression. I didn’t pay much attention to the DMDD diagnosis, as all the professionals that were treating him were telling me that it was the PTSD that was driving his dysfunction. Ben attended several weekly appointments, including occupational therapy, counseling, community-based rehabilitation, medication

management and others. During all of this, I attended college from 2012 to 2016, and received my degrees in Sociology and Psychology. I did this out of desperation, as I could find no one that could figure out what was driving my son's behavior, or how to mitigate it in any way, other than keeping him sedated."

Patrick: "The preliminary diagnoses and therapies seemed endless: ADHD, ODD, SPD, RAD, ASD, FAS, and food sensitivities. Even spiritual warfare was suggested. But at three years old, all diagnoses were held loosely. We did two years of OT for suspected sensory processing, and an exercise program three times a day. We tried gluten-free and dairy-free diets. We did food sensitivity testing and worked with a naturopathic doctor. We saw a play therapist and parenting coach weekly. We had him evaluated by the early education team through our public school system, who noted he was highly intelligent but yet, couldn't see how puzzle pieces fit together. They refused any services or further testing to investigate our reports from home. The psychologist was hesitant to diagnose at first. Patrick was now six, and while we had a lot of data, his behavior didn't fall squarely into traditional ADHD or even RAD categories. Over the months that followed, we tried several different medications: escitalopram, Depakote ER, guanfacine ER, and methylphenidate ER. Each had a glimmer of hope at the beginning, but within weeks, would lead to an increased frequency and severity in rages. During the summer, Patrick tried Zoloft and stayed in a manic state for weeks."

Jonas: "By the time Jonas was eight, the dynamics were starting to change. He was getting bigger and stronger and becoming a much bigger physical threat to everyone in the family. We made the decision to make an appointment for a full psychological evaluation, after which he was diagnosed with DMDD. I think it is critical to point out that the only reason he received this

diagnosis was because we homeschooled, and the behaviors were being seen in ‘multiple settings.’ I was told that if his evaluation had happened while he was in a public or private school setting, and they were not seeing the behaviors there, he would not have been diagnosed. His behavior would have been written off, once again, as poor parenting.

After the diagnosis, we tried Zoloft. It seemed to make him hyperactive, more impulsive, and he had difficulty sleeping. We tried Trileptal (low dose) for about a month and it seemed to do nothing; I had not yet heard of Dr. Matthews’ protocol. Next, we tried Abilify. Within a week, we noticed a big change. Jonas did too. He said, ‘I just feel happy.’ But slowly, the behaviors crept back in. We increased his dosage, and his weight increased as well. He was not as physically aggressive as he was before, but still very irritable and would have moderate rages, multiple times a week. After a move, we changed psychiatrists and decided that Abilify was not really working for Jonas. Next up was Lamictal. It took about six months to come off of Abilify and titrate up on Lamictal. It was hard. Jonas started getting much more physical with us. However, at the end of the titration period, he was beginning to improve. He seemed to have more control of himself when he would get angry. Unfortunately, he still got angry and seemed irritable much of the time. But controlled anger is an improvement over uncontrolled anger.”

Bella and Lizzie: “By the time they got to third grade, we were at our wit’s end with their behaviors, so we made an appointment with a child psychiatrist. That started us down a road which would turn out to be much longer, and more complicated, than we could have anticipated. The first diagnoses that we received for Bella and Lizzie were anxiety and depression. Approximately six months later, they were also diagnosed with DMDD. They had neuropsych testing during this time as well (age 9), and at that point, Lizzie also received a diagnosis of

selective mutism. This is something that she has seemed to 'outgrow' over the years, although it's still very difficult for her to speak in new/scary situations. Bella has had a number of tics over these years and was diagnosed with a tic disorder during that same initial time frame. Lizzie has been treated for OCD symptoms for quite some time, although I'm not sure that it was ever officially diagnosed. Her sensory issues have been attributed to OCD. We had one psychiatrist (we went through several during those first years) who did attach an autism diagnosis to both girls. There was never any formal testing or even real questioning/discussion about it. This was in 2019, after their initial hospitalizations, when they were about 12.

The psychiatrist started with guanfacine ER, which seemed to have no noticeable benefit. Over the next many years, the girls were tried on multiple anxiety and antidepressant medications, most of which have not shown any noticeable improvement. Both were started on Abilify at some point (around 10 or 11) which also didn't seem to have much of an effect. As the dosage increased, so did their weight, and they ended up each gaining 50-60 pounds in about 18 months, from the age of 12-13. This was disastrous for a couple of middle-school girls who already had significant self-esteem issues. Both girls had GeneSight testing done way back at the beginning, but we haven't really found the results to be very helpful or even accurate.

There were a couple of medications that I definitely noticed some initial improvement with Lizzie. She was started on Lexapro at about age 11, and within just a few days, I noticed a positive difference. It was like a more chill version of Lizzie – she was able to go with the flow a bit more, wasn't so uptight and anxious about every little thing. Sadly, it seemed to slowly lose its effect after a few months. The only other medication where I really noticed a difference was Prozac. Lizzie was started on this during one of her inpatient hospitalizations, as the doc said that

it was sometimes found to help with OCD symptoms. He felt like it may help with Lizzie's sensory issues, and it really did seem to help, at least to some extent. She is still on Prozac, about four years later, but has been tapering off of it lately, as we are trying to figure out if it is still effective at all. Bipolar disorder has also been considered for Lizzie in the past months, although no conclusions have been drawn. This is due to Lizzie's baseline depression, which has been a big part of her struggles since about the age of 10, or maybe even younger. That is why we did a trial of ketamine during the summer and fall of 2022. She did about eight sessions, and initially, I felt like there was some improvement in her overall mood, but in the end, she hated how the ketamine made her feel and was frightened during the sessions."

Barry: "He was in second grade and about the same size as me, and he still feels humiliated by the experience. About the same time, he had a meltdown in class and a psychiatrist diagnosed ADHD and started him on Concerta, a medication that helped him for many years. Unfortunately, he couldn't tolerate it any longer when he reached puberty, and we had to take him off it. At that point, my son started on Abilify. This too helped, but we had to increase the dose three times, and eventually it lost its effectiveness. My son became obese, developed breasts, and the rages continued. He was miserable, and I dreaded picking him up from school every day. When the stresses of academics and peers and trying to control himself became too much, he would take it out on me, going into long tirades that were awful to endure. We were under the care of a psychiatrist, but we didn't have a diagnosis. I did some research and talked to the doctor if it could be DMDD? However, he was skeptical since DMDD is a relatively new diagnosis. Our doctor asked ME to explain how it differs from bipolar! When I told our doctor

what our son looked like when raged, and then collapsed – not remembering any of it -- he said, ‘You’ve just described exactly what a partial seizure looks like.’”

Michael (age 15): “We adopted Michael from birth,” says his mother. “He was in second grade when diagnosed with ADHD. We first tried alternative treatments that included: Brain Balance (a program we did 3x a week, for six months), food sensitivity testing, elimination diet, limited screen time, Japanese tinctures, neurofeedback and biofeedback. Nothing really helped, so we had to resort to medication. While on Concerta, he was the model student, but every afternoon, he crashed with meltdowns. When he maxed out on the medicine, he was switched to Vyvanse, making Michael increasingly agitated, anxious, and losing weight. We also noticed his aggression at school was kicking up, and the principal, who now had her own ringtone, was calling daily. Then, one night, Michael had the worst rage we had ever seen up until that point, which lasted for two hours. He tore up his room, taking the mattress off his bed, flinging heavy toys and objects at us. Then, holding his head, screaming, 'Mommy, help me!' while at the same time biting my arm and spitting in my face. Michael was only 65 pounds, yet my husband and I could not restrain him, as he was incredibly strong. It was the first time we ever heard our son growl like an animal, and his eyes had this blank stare — it wasn't him and it was frightening. My husband and I both realized it was the Vyvanse. The very next night, we had the same situation all over again. Since our psychiatrist couldn't see us for three weeks, we got a new one, as we were in crisis. Michael was then diagnosed with pediatric bipolar. We tried Lamictal but he got a rash, so he was taken off of it and pumped up with prednisone for weeks. Next, we tried Trileptal (generic) but noticed all the extra saliva he was spitting out (an extremely rare side effect), so that medication was pulled. He was then put on lithium, but now his behavior alternated from

happy to angry, from morning to night. From my research, I thought he had symptoms of DMDD and not bipolar. We got a second evaluation from another psychiatrist, who diagnosed Michael with ADHD and DMDD. The doctor told us that depending on where you live in the country, you will either get a diagnosis of bipolar or DMDD. He advised us to keep him on lithium. In a short time, Michael gained 30 pounds, his hair went from straight to very tight curls, and he now had a thyroid problem from the lithium. When he threatened to kill himself and everyone else at school (he was in 5th grade), we were told to get him evaluated before he could return, so we brought him to a psychiatric hospital. After the social worker interviewed us, she said we needed to make the decision if we wanted Michael to be admitted. He seemed fine now, even sweet. We asked our son, who was 10 at the time, how he would feel about staying at the hospital for a few days? Without hesitation, Michael said, 'I want to stay. I need help with my anger.' My heart sank. At that moment, I knew our son realized he was sick. After two weeks, he was discharged, and no better, even with the addition of clonidine.”

Nathan: “When we finally were able to get him an NHS appointment to see a pediatrician, we were expecting a diagnosis of ADHD. However, the pediatrician said that it was their policy to not diagnose ADHD until age six, and Nathan was only four. What surprised us was that the pediatrician diagnosed autism spectrum disorder (ASD). I attended a series of 10 weekly educational sessions, set up by the National Autistic Society, a UK charity for autistic people and their families. While I learned a lot about autism, I also learned that Nathan was very different from other children with autism. I tried to implement the strategies I learned, but they mostly irritated him. He ripped the visual timetable off the wall and tore it in half. He ignored the reward chart entirely and would get violent whenever we mentioned it. Whatever the reason was, it was

clear that these autism strategies were causing my son more distress, so we stopped attempting them. After months of begging the NHS pediatrician to diagnose ADHD and prescribe stimulant medication, she did. It was heart-breaking to witness him getting worse on methylphenidate. We gave him a dose in the morning, which seemed to make him more hyperactive. But by the evening, when it should have mostly been metabolized, he was raging into the early hours of the morning. He refused to settle in bed. When he was sternly told to stay in his room, he started to scream and hit us. He turned his room upside down, throwing furniture at the walls and snapping toys in half. It was, by far, the largest episode of rage Nathan had ever experienced. And it was clear to me that this was triggered (if not caused) by methylphenidate. Next, we tried guanfacine ER, but after a few weeks, he had no noticeable effect on this medication. We were in a crisis. Our son was raging about three times per day. We found a highly recommended, pediatric psychiatrist who specializes in ADHD, and took Nathan to see him a few months after his sixth birthday. The psychiatrist, who was a professor, had worked for decades heading a department at one of the country's hospitals for children who need highly specialized care. He said Nathan was 'extraordinarily' hyperactive. Examining him or asking him questions was very difficult, as he exited the room after a few minutes, and was racing up and down stairs and through the corridors of the building. The psychiatrist agreed that ADHD and ASD were correct diagnoses, and mentioned DMDD, which we had never heard of before. He said it was unusual to be diagnosed in the UK, but it captured the violent outbursts we described. At one point during the appointment, he had us describe the help we had received so far, and he responded by saying that nothing is likely to work until a suitable medication is found to help with the hyperactivity and the rages. For one moment, the psychiatrist suddenly got very serious, looked me in the eye

and said, 'You're going to have to fight like hell for this kid, even if it means remortgaging your house.' That was the moment when it became clear that Nathan's psychiatric problems were severe. First, we did short trials of every type of ADHD medication. None of them had any positive effect on my son's rage problem. Next were antipsychotics, which sedated our son and had no positive benefit. They also vastly increased his appetite, along with his weight. By the time we got to memantine, which seemed to produce small improvements, our psychiatrist had run out of recommendations. We were desperate for an expert to make things better for our son, but no such expert seemed to exist."

Jeffrey: "He was four and a half when he was diagnosed with autism. We had more testing done and were told Jeffrey had ADHD and depression. When he was seven, he started on Vyvanse, but it wasn't good for him. He then tried Abilify, Prozac, and risperidone. The Abilify made him extremely sad or extremely angry, and we didn't seem to have any in-between moments. The Prozac made him suicidal. The risperidone worked for him, but the issue was that the pharmacy never had it in stock, and at that time, all he would take was liquid medication. He started Zoloft, and that increased the suicidal ideations. June 2021 was the first time he received inpatient treatment for one week. He started Seroquel 25 mg during the day and 50 mg at night in treatment, and he discontinued Zoloft and Abilify. He came home with new medication, the same explosive behaviors, and a new diagnosis, DMDD, on his discharge paperwork. No one had shared with us, or even stopped to explain this disorder."

Kevin (age 15): Kevin's mom shares, "By age five, we experienced my son's first hospitalization, after showing extremely aggressive and violent behaviors. We knew nothing about what may be going on with Kevin, or how to best seek additional help. Turns out, sedation

was their answer, before I knew any better. With him being so young, our options with medications were limited. He was there for two weeks, came home sedated, and within a few months, we were back to where we started. Off to new medication management providers for the next eight years, going through a total of 23 different medications. We had the behavioral ‘specialists’, the therapists, yet no one was successful. One of the worst parts of this leg of the journey was thinking it was a behavioral issue and not an actual neurological issue. I am still traumatized, thinking of all the consequences my child endured, not knowing it was something he absolutely could not control. Nothing worked long-term for our child. You name it, we were on it: Abilify, risperidone, and then came the attempts to alleviate the ADHD symptoms with stimulants. What an absolute nightmare. Kevin was in kindergarten and first grade during this traumatic time in our lives. He was constantly sent home for his outbursts, and I dreaded seeing the school’s number appear on my phone. Nothing was working, and in fact, some were making him so much worse. We later endured three more hospital stays and one and a half years in a residential treatment facility. The worst experience of our lives, and my child is still traumatized by the experiences in all of these places. No matter how much I tell myself that it was the only thing I knew to do, or that it was the best way to keep him safe, the guilt still plays in my head.

If there is truly a silver lining in all of this, it was the medical professional at the residential placement that determined it was DMDD. By this time, we had been given multiple diagnoses, both on and off the autism spectrum. When DMDD entered the picture, regardless of adding another set of letters to his name, I began my own research, asking, how do we ‘fix’ my child? The first course of action was Seroquel and lithium. If I knew then what I know now, lithium would

not have touched my child's body. A provider told me once accustomed to sedation medications, they no longer work and there will come a point when he needs to be off one and onto another."

Julia (age 13): "Julia has suffered from anxiety since her preschool years," says her mother. "Her behavior grew out of control, and her overall mood and demeanor were troubling. She became increasingly irritable, highly reactive to the smallest things, had outbursts several times a week that took hours to get through, became increasingly fearful of the world around her, making it nearly impossible to sleep. We had been seeing a therapist regularly, along with a psychiatrist. Despite trying a variety of medications, ranging from a litany of antidepressants to stimulants, and even going so far as trying antipsychotics, out of complete desperation, we were making no progress. On top of medications, we invested tens of thousands of dollars in therapy (CBT, play therapy, talk therapy), neurofeedback sessions and biomedical interventions. Nothing helped. Things got worse as she began third grade. I was getting calls almost daily from school, and started looking at inpatient treatment centers, as we were desperate for relief. Our family was in a state of crisis."

Zack and Annie: "We were advised initially by our psychiatrist that our son only had ADHD, despite the tearful, pleading phone conversations, describing the worsening aggression that we were experiencing. Abilify was prescribed, and it did curb the aggression quickly. The problem, however, was that we had to keep increasing the dosage to get the same results, and our son gained 40 pounds in the process. The doctor weaned the Abilify very quickly, without adding another medication in its place, and our son was promptly hospitalized for a week. The aggression during the Abilify wean was outrageous. I would honestly compare the intensity to childbirth. Zack's first hospitalization was at the age of 11. He had three inpatient stays and three

outpatient ones. He was inpatient for a total of about three weeks, and one week was for the Abilify wean. Zack was diagnosed with DMDD at age 11, and then with autism at age 13.

In the meantime, our daughter, Annie, also started having mood issues. I was told by the local hospital that it was trauma from our situation. After having a trained mentor observe us in our home for a couple of months, she agreed that this was likely a mood disorder. Annie had become increasingly irritable, lost her friends, quit showering, and sometimes exhibited aggression. For her, the rages were more verbal than physical. They were happening more than once a day and were the kind of tantrums that would give you a severe headache. Annie was 10 when she was diagnosed with DMDD.”

Eileen: “From ages 7 to 12, my daughter was given the diagnosis of childhood bipolar disorder. We never knew what would set her off. A reprimand, teasing from her brother, a wayward clothing seam, unapproved meal choice. We walked on eggshells. I kept telling everyone this wasn’t bipolar. I personally would grapple with the rollercoaster of emotions: happy one moment, sad later that day. There were whispers of the potential of schizophrenia. We went through at least three psychiatric practitioners. Over those years, providers prescribed all the antipsychotics, which caused her to either have tics, gain weight or they simply didn’t work. They added antidepressants, therapy, and discipline. Nothing worked. Nobody listened to me. She raged on and on and on. Broken electronics, nearly broken body parts (mine), severed friendships, and the school had me on speed dial. As someone who is manic-depressive, I knew the bipolar diagnosis was wrong, because nothing Eileen did was similar to my life, actions or childhood. I didn’t explode like Eileen. I didn’t break things like she did. I didn’t hit or hurt people like Eileen did. I knew they were wrong, and yet nobody would listen to me. After a suicide

attempt at age 12 (almost jumping from our fifth-floor hotel balcony), because I had asked her to brush her teeth, we were back in inpatient for the second time (first was age 7). It was there that she was given the diagnosis of DMDD (something that made sense when I looked it up), ASD (which everyone poo-pooed, but I knew it was accurate), PDA (a kissing cousin to DMDD, if you will) and ADHD. These simple acronyms helped us start putting the pieces of the puzzle together and getting her on the right track to treatment.”

Jordan: “We first ventured through using supplements. And while they offered some help, it was never enough. Despite my total resistance, I agreed to try a diet free of gluten and Red 40. As insistent as I was to not make diet changes, it became apparent that avoiding them really was necessary, as there was a marked difference in his mood and emotions when he ate either of these. Still, behaviors and big emotions were emerging and starting to be more problematic in school. In second grade, things got more intense. His diagnosis began as ADHD. We tried a host of medications over the next couple of years. Some medications made his behaviors escalate even more. Prozac even caused him to lock out the babysitter and get physically aggressive with siblings. We worked with various anxiety, depression, and ADHD medications. But we continued to struggle to find any medication that would work for very long. If they worked at all, they would only work for a short time and suddenly stop. We started to realize that we needed to treat the anxiety, as well as address the sensory processing struggles that we were discovering. The challenge was that in treating ADHD, we needed to stimulate his brain, which in turn stimulated the anxiety. If we calmed the anxiety, it exacerbated the lack of stimulation associated with the ADHD. So, we could never find a medication that addressed the totality of what he was feeling. His diagnosis kind of morphed. Around the end of third grade, we

were treating him for depression. The medications were still a mess. Some caused him to become more agitated and some to be even more aggressive. It was a nightmare by fourth grade.

At this time, I began researching DMDD. I found a doctor that would work with Dr. Matthews' protocol. We made some various medication changes. He continued to still struggle and ended up having to be evaluated at the hospital with suicidal ideation. At this point, I asked the doctor if we could do a GeneSight test and start the protocol. We did. Officially, his diagnosis has included ADHD, anxiety, depression, and unspecified mood disorder. Matthews' protocol has been a miracle, though. I asked the doctor if that confirmed that it was indeed DMDD, since this protocol was the only thing that had helped and had made such a remarkable difference. He said maybe, however, his record still indicated the unspecified mood disorder. So, I sensed that he wasn't really wanting to specify officially on record. I have had other parents voice the same and wonder if it is a common response from doctors."

Puberty

Parents in this section share what puberty is like for a child with DMDD. As their children's bodies are changing, many parents have found that medication adjustments need to be made. Some teens receive a new diagnosis of autism, anxiety, and/or depression during this stage of their life. While puberty can be a roller coaster for most, one parent shared that it had been rather uneventful in their particular case.

Julia: “My daughter suffers from anxiety and has needed added emotional support, particularly through the puberty years. That said, she is showing continued progress, and we remain hopeful about her future and her ability to lead a normal, productive life.”

Cid: “He’s struggling with delayed puberty, which is aligned with his growth hormone deficiency. Cid’s behaviors changed from when he was a young child to his tween years. His younger episodes were all meltdowns, and his tween episodes were much angrier.”

Eileen: “We didn’t get the DMDD diagnosis until puberty was in full swing. We found that adding Lo Loestrin Fe birth control helped level out her moods. This delivers a dose of hormones daily, so she doesn’t have a period - great news for my hygiene-challenged child.”

Kevin: “Puberty did not affect him much. He had a slight increase of irritability, which prompted us to increase his Trileptal by a small amount. We also increased his anxiety medication. Once he was stable, we had no other increases during puberty aside from this.”

Bella and Lizzie: “As we set up camp in the ER with our girls, we waited for 10 days before both were placed. It seemed like the nightmare just kept getting worse. It was shortly after the twins’ 12th birthday that Lizzie got her period for the first time on that hospital cot. Bella got hers a few months later. In hindsight, we could look back and see that the worst time for us, as far as the girls’ behaviors, was right as the girls were hitting puberty.”

Lila: “My daughter had been relatively stable on Trileptal, amantadine, Vyvanse and Prozac for a couple of years. Around the time she turned 10, old behaviors came back, along with some new, worrying ones. She started getting aggressive again, especially when social situations didn’t go her way. She became more irritable and argumentative. And she had a lot of negative talk about herself. We realized she was in the midst of puberty and had to make a few changes.

We started tracking her moods to see if there were hormonal patterns to her behaviors. We also went for a full blood work-up and discovered that her Trileptal level was low (out of therapeutic range). We had not increased it to keep up with her weight, so we increased the Trileptal. Things got rough for about a week, with daily outbursts at school and unusual irritability at home, but things did calm down and she seemed to re-stabilize. We now check her Trileptal levels every six months, so we don't slide back."

Michael: "It wasn't until puberty that we noticed anxiety about going to school. He was prescribed Gabapentin, but things escalated, and he landed in the hospital. I was told he had anxiety and depression, but it was showing up as anger. While in the hospital, they tried a few anti-anxiety meds, until we found Lexapro to help Michael. It was during that time he was diagnosed for the first time as having high-functioning autism, and we were surprised. I've also noticed during puberty that his Trileptal blood levels fluctuate often, so we continue to adjust his medication with small increases or decreases, which gets him back to stability."

Zack and Annie: "At 13, Zack was diagnosed with autism. We noticed his Trileptal blood levels would go up and down during puberty, so adjusting the dosage was tricky. Annie needed more Trileptal during puberty, probably due to her weight gain. We also did need to add a stimulant during this time as well."

Struggles in School

It is common for parents of DMDD children to report behaviors that take place at school, as well as at home. In some cases, parents claim that their children have no issues at school, despite the violence at home and other locations. Parents dread seeing their child's school

number on their phone, as it is always attached to a negative complaint. Parents explain how their children need services and assistance in a school setting to help them succeed. Most parents find that their child goes from a 504 plan, to eventually requiring an Individualized Education Plan (IEP). Parents struggle to know what services are available as well as how to request them. They often feel at the mercy of the school district, as the school is not typically eager to divulge this information. For children who have not been evaluated by an educational diagnostician (they might have only a 504 plan, or even no plan at all), it is common for them to be harshly disciplined for their disability. Parents have attested to school suspensions happening as early as kindergarten, as well as children being arrested for DMDD behavior as early as elementary school. Hiring a special education advocate has been necessary for most parents to successfully navigate the public school system, and therefore receive appropriate accommodations for their struggling children.

Carson: “At the age of six and seven, Carson had out-of-school and in-school suspensions, for physical violence towards other students. At age eight, Carson was kicked out of the after-school childcare program. He had school refusals. He became physically violent with staff and continued to be violent with other students. After seeking assistance from a special education advocate, Carson received an IEP. He is receiving services under ‘Otherwise Health Impaired.’ I have educated school staff about DMDD and how to prevent rages. It is still difficult because people think it is a choice and ‘Carson should know better.’ I still fear any text I receive from school, because I have been contacted many times to pick him up. Despite my son’s SPED designation, we still get staff asking about consequences at home and what we are doing to prevent behaviors at school. Again, they are implying that his behaviors are a choice.”

Ben: “After a formal evaluation and IEP, Ben remained in special enclosed classrooms for five years, which each had a locking, padded room that he was placed in several times a week. He became more violent and unpredictable, lashing out for no reason. I was called into the school multiple times each week, to either intervene or bring him home. He lost trust in staff and was moved every year, with a new teacher and school in the hopes that he would find stability. But despite these attempts, school remained an immense stressor. He didn’t have friends at school, since his behavior was so violent, and no one wanted to be around him.”

Jordan: Jordan’s mother, who is a behavioral health professional, also found difficulty in helping her son find the right services, as well as successfully advocating for him. “Jordan’s frustrations at school increased. His classroom teacher didn’t really understand his issues and chalked it all up to choice and defiance. She resisted using strategies that she considered to be rewarding of his bad behavior. Fortunately, we had a school staff member that truly did understand and helped advocate for Jordan. But by the next year, we experienced less support in the school setting. My lack of knowledge in advocating for special education services and appropriate follow through with his individualized behavior plan, caused the school situation to become quite troubling. Each day, I dreaded a call from school and a lapse in following the designated plan for his protection.

At our lowest point, he had been suspended from school for losing control of his emotions, after they had accused him of wrongdoing. They later discovered by video that he actually had not done what they accused him of, but the damage of his actions following the accusation, brought the consequences. He felt consistently rejected, analyzed, and under a microscope with all he did. He thought the teachers were constantly angry at him, as evidenced

by their 'low, slow, mad voices' as he described it. He continued to struggle with low self-esteem, and his talk of wanting to die increased, even in front of his peers."

Jeffrey: "When Jeffrey was 10 and in 5th grade, he had a behavior plan that the school, in hindsight, had not been followed. I received a call one day, stating that he had attacked a faculty member, and was heading to the juvenile detention center with police officers. This started month of psychiatric hospital visits and pediatric hospital stays, trying to get him the help he needed. Upon his return to school, I provided his new diagnosis, a treatment plan from the facility, and stacks of paperwork for the team. Unfortunately, simply providing this information doesn't mean that a plan will be put into place, but we didn't know that at the time. Evaluations that have to be formally requested, yet we were not made aware of these processes by the school. What was even worse, the paperwork I had provided them was lost. His behaviors were regarded as delinquent behaviors, instead of a manifestation of his multiple disabilities, for which I had provided ample documentation. He was punished often and spent a great deal of his 5th grade year outside of a traditional classroom setting. We had to have several meetings and hired an attorney, as well as multiple family advocates. We had to educate the school about DMDD. A year later, we seem to be on the same page now."

Patrick: "We had him evaluated by the early education team through our public school system, who noted he was highly intelligent, but thought it was odd that he couldn't see how puzzle pieces fit together. They refused any services or further testing to investigate our reports from home. Ultimately, we decided to start kindergarten at public school because they were legally obligated to work with him. We were reassured by the principal that they understood difficult kids, and that Patrick would fall into a rhythm with the new routine. But within weeks,

we were called in to start a behavioral intervention plan. He couldn't keep his hands off other students and would threaten harm to teachers when he was asked to do things. In the first grade, Patrick got mad at recess, hit a teacher, and tried to run away from school. The school was resistant at first to start a 504 plan and said we needed an official diagnosis. His psychologist said if he had to diagnose at this age, he would call it DMDD. With the 504 in place, Patrick's teachers had solid ideas for smoother transitions between activities, were able to give him breaks from the classroom, provided scheduled check-ins with a trusted counselor, and got him enrolled in social skills classes through the school. It helped for a while, but like all things with Patrick, as soon as the novelty wore off, the old behaviors quickly returned. We fought to establish an IEP, which provided Patrick with specific goals and access to a paraprofessional aid that would help him process things if needed. He had morning check-ins to prevent irritability from escalating. The school even matched him to mentor an autistic child, which helped him learn empathy and focus on someone other than himself. He tested into the academically and intellectually gifted program and was challenged with books and conversations that stimulated him."

Kellan: "Kellan was first evaluated by the early education program in our school district, and qualified for services as he was turning 4. He stopped attending regular daycare/preschool, where he had been expelled, and now attended the early learning school for three hours a day, where he would receive behavioral skills lessons. Kellan was frequently aggressive and violent when told 'no,' or when other students would take toys he wanted. He was extremely depressed during this time and spoke frequently about wanting to die. He started kindergarten with his peers, which proved to be problematic, even with the information from his prior evaluation. His sensory issues, along with being prone to overstimulation, triggered him frequently. When he did

not escape from the school building, he went into violent rages, where he would destroy entire classrooms and rage for 30-60 minutes. The school wanted him to be formally evaluated to qualify him for a more secure campus. We had zero guidance. Had the school not provided these services or options to us, we would have had no way of knowing what was possible. We truly were at their mercy. After Kellan's evaluation, he received services under 'Otherwise Health Impaired' and an IEP was put into place for him. The district also moved him to a school with a special behavior classroom, with an adjacent, padded room for outbursts. The staff that worked with him were highly qualified, and the school was much more secure, with multiple sets of locking doors. Even then, he managed to escape the school grounds on more than one occasion."

Bella and Lizzie: "School was one of the most puzzling aspects of this whole experience for us. The twins did not like going to school, and with each passing year, their anxiety and aversion to school seemed to worsen. Their attendance became more and more sporadic, which in turn caused them to fall behind and not know why, which in turn, caused their grades to worsen, which would cause them to despise school even more. What a vicious cycle we were all caught up in. When the girls did make it to school, however, there were never any negative behavioral issues reported, and when I would speak to teachers at parent/teacher conferences and ask about behaviors, they couldn't even imagine them acting out in any way. Their middle school counselor felt that when at school each day, the girls were bottling up their emotions and interactions collected throughout the day, such as the fear of being made fun of, teased, or heaven forbid, looked at. She compared them to a 'bottle of soda being shaken slowly over the course of a day' that would then often explode after arriving home to their safe space. Bella and Lizzie suffer from what is often referred to as the 'spotlight phenomenon', where they always

feel as though someone is looking at them or judging them. Initially, 504 plans were implemented for the girls in 4th grade, and by 7th grade, they ended up qualifying for IEPs which have helped them be more successful.”

Police and CPS

Many parents of children with DMDD have needed the assistance of the police during an outburst to protect their family and their child from hurting themselves. In other instances, police were called when their child had eloped from home or school. In some cases, the outburst is so severe, parents have called 911 for help transport their child to the hospital. Additionally, an encounter with police and violence at school usually results in a call to DHS or Child Protective Services (CPS) as teachers and police officers are required to make a report.

Bella and Lizzie: “Visits and questioning from CPS occurred on several occasions. We also had multiple visits from our local police department and had to stand by helplessly as they entered our home. These visits would involve breaking interior doors off their hinges, tackling the girls, pinning them down, handcuffing them or strapping them to stretchers, and hauling them off to hospitals and police stations. On one occasion, my husband and I got home to find that after a fight with their older sister, Bella and Lizzie had run to a new neighbor’s house, one who didn’t know us or our situation. The startled neighbor called the police and refused to allow the twins to return to us until the police arrived. On another occasion, the girls were hurting each other in the car to the extent that I pulled over and dialed 9-1-1. The police officer that responded was a very angry man, and it was evident that he wished he could do as he pleased with them. Although I could understand his feelings of wanting to show them ‘who was boss,’ it was

completely unnerving to have the authority who was supposed to be helping us, seem like he was about to lose control as well.”

Zack: “The police were frequently at our home, and sometimes our son was strapped down and taken by ambulance to the hospital.”

Cid: “We had to call the police a few times as we began our medication journey with Cid. He wanted family night every night and wanted to watch a movie of his choice, where his sister and I put our electronics away. Cid’s sister had schoolwork to complete, so I suggested a family game for 30 minutes, instead of a family movie for two hours. Cid lost it. He grabbed a butter knife and gestured to slit his wrists. He then ran into the garage and found scissors. He started stabbing everything in sight. I knew I could not take the scissors away safely, so I locked him in the garage and called 9-1-1. Cid was stabbing until he heard the sirens. Then he started to panic. He begged me to tell them to leave. He pleaded with me that he was done being angry. The 9-1-1 operator instructed me to not open the door until they arrived. I apologized and explained to Cid that it was too late at that point. The police circled the garage, and I opened the door from the outside, using the code. The police officers were extremely helpful. They helped him take his meds. They told him that we cared for him. Cid was calm for 30 minutes. Once the fear that they would take him to the hospital was gone, he immediately had another episode. We only had one CPS incident. Cid came home with a bruise the size of a tennis ball on his hip from school. Because Cid has two homes, my home and his father’s home, we could not pinpoint where the bruise had come from. The school thought it happened at home and called CPS. The case was dismissed quickly. For years, I could not understand why Cid could not remember the details surrounding such a painful bruise. When I learned that it is possible for DMDD children to

not remember what happens during an outburst, I realized it was likely that he wasn't hiding what happened, but actually didn't remember."

Kellan: "Our first encounter with the police was when, at age five, Kellan ran from his grandmother and ended up in the middle of a busy road during rush hour. The police officer put my son in the squad car and came to our home to talk to us, without even telling us where our son was or what had happened. We were panicking! And he allowed us to panic for a further 10 to 15 minutes, before telling us that our son was in his squad car. This infuriated my son's father, who is also a police officer and had rushed home from his shift, arriving at the same time as the other officer. We tried explaining that our son had a lot of issues and had even spent weeks in a pediatric psychiatric ward a few months before, and that we were doing what we could. We were still referred to CPS over the incident, despite everything we were doing, and his police officer father trying to explain as well. When CPS eventually arrived, I was prepared with guidance by my own therapist, who had been with me every step of the way in my struggles. I was able to provide the CPS worker with the business cards of my therapist and that of my son's therapist, his formal school evaluation and IEP plan, as well as his paperwork from the hospital. I also showed her the alarm system we had installed on the doors, to alert us if he tried to leave the house. The CPS worker had enough documentation for the incident to be resolved. Police were called on two other occasions by Kellan's school, when he eloped from the building and school property. In one of those situations, he was upset that they were trying to put him on a different bus. Kellan knew what his bus looked like and the number of his bus. The bus that arrived was indeed a different bus, and he panicked and ran away from the school."

Jeffrey: “I received a call stating that my son had attacked a staff member at school and was heading to the juvenile detention center with police officers. After he was released to us, we went into a room to sign paperwork, where the police interrogator informed us that they believed he was also autistic. Triggered by this statement from the officer, my son lunged at the interviewer with a pen, and the situation escalated quickly. EMSA had to be called to transport him to the hospital, as he was homicidal and needed psychiatric treatment. Unfortunately, our local psychiatric hospital turned down our request for services because of his disability. We were directed to a pediatric emergency room, where he stayed for the second time. During our previous two-week stay at the pediatric emergency department, both my employer and my husband’s employer had been flexible with us, but this time, they were making no concessions. We also felt like our son was making no progress while there. We requested to have our son discharged, and requested the list of psychiatric hospitals they were contacting on our behalf. We were then warned that discharging him would be considered neglecting our son. A DHS investigator showed up at our home the following Saturday morning, and my son saw her as a threat. He began throwing shoes and hangers at her. He struck her with a Boy Scout belt before running back to his room. The DHS worker then threatened to remove him from our home right then. Our son ran, and police officers were called to search for him. In the process of getting him back home safely, he kicked an officer and threw a water meter lid at him. Jeffrey was later charged with assault, for kicking the officer and throwing the cover. We had to hire an attorney, and it took months of court appearances for it to be resolved. The DHS investigation continued with unannounced drop-ins, phone calls, as well as scheduled check-ins. This went back and forth for months. Throughout this time, we continued with his therapy treatments, medication

treatment, and established rules. Our parenting skills and relationships with our children were questioned, and the school was also interviewed, in addition to friends and family.”

Relationships

When the pandemic happened, it brought about a social isolation of immense proportion that impacted society as a whole. However, for many DMDD families, it felt like the world had finally caught up to their reality of living in isolation, something many of them had been doing long before the pandemic. Unfortunately, it's all too common that due to their children's unusual and even scary behaviors, invitations for holiday gatherings and parties from extended family members or friends gradually stopped. These parents have often had to learn the hard way that there is a big difference between a mentally ill child in the hospital versus a physically sick one. They don't post on social media for prayers and support, for fear of being judged, nor do they receive warm casseroles or dinners to help lighten their burden. No, these parents have kept the horror show they've been living to themselves, to avoid further embarrassment and potential scrutiny. Parents have expressed the post-traumatic stress they and their other children have endured, from walking on eggshells to avoid setting off another rage. While out in public, parents have reported that strangers are often too quick to offer unsolicited advice or make assumptions, which only inflicts on them another level of pain, discomfort and even shame. Online DMDD communities are often where parents eventually turn for solace, advice, and solidarity.

Kevin: “We did not come out of this unscathed. There is a tremendous amount of PTSD that our family has suffered, and the relationship with my husband ended for a period of time. This is not the child's disorder – it's the family's disorder and needs to be recognized as such.

Not only does this isolate the children, but also the caregivers. Family members and lifelong friends often do not understand, which makes this journey even harder when your support system is broken.”

Ben: “My son’s behavior caused immense strains on relationships with those around us. My mother told me he looked possessed when he was in a rage, and that I needed to have him exorcized. My sister uninvited us from her wedding, claiming that he would ruin it. We were never invited to family events or holidays, as he was viewed as being intentionally out of control. I was told constantly that I needed to put him in an institution. I begged my family to understand that he wasn’t intentionally doing anything. I tried for years to make them see that it was like a switch flipped in him, and he lost control. No one would listen. He didn’t have friends at school, since his behavior was so violent, and no one wanted him around. Our world became so small. The judgment from strangers was one thing, but hurtful words from family was the worst.”

Jordan: “As a mother and therapist, I understand why Jordan’s violent rages have been traumatic for our family, which includes six other children. It’s brought us all a bit of PTSD from walking on eggshells, never knowing if a small emotion would erupt into an all-out rage.”

Patrick: “During the fall of Patrick’s kindergarten year, we adopted our third son. We wanted our second son to have a companion. But it was not safe to leave Patrick alone with the baby or the toddler. He would not follow instructions, and intentionally subjected harm on them when I wasn’t looking. It was a constant juggle to keep everyone safe. My toddler would sense one of Patrick’s rages coming on and would carry the baby to his room to protect them both.

Patrick has shaped our marriage and family in more ways than we had ever imagined. We've shifted careers, moved homes, adopted less children than we originally intended, and hired help out of desperation. Our other boys have attended therapy to process traumatic events caused by Patrick's outbursts. Now nine and six years old, they both try to have a relationship with their brother but are rightfully cautious and quick to find blame. We have been to marriage counseling to help us process how Patrick has influenced us individually and as a couple, and to learn to reconnect without him in the middle."

Nathan: "We have found DMDD to be very isolating. We've never met another child diagnosed with DMDD, nor have we met other parents who have dealt with this disorder. When strangers offer their advice, it can often arrive at the worst times, such as when your child is in crisis. Frequently, I receive advice from middle-aged women who judge me to be an inexperienced and incompetent dad in need of instruction. I'm not one of those dads, but also my situation is far too complicated to explain. It's a wonderful privilege to be able to use the internet to connect with other parents from around the world who have children with chronic irritability. I've learned more from them than from any other source."

Bella and Lizzie: "Bella and Lizzie were separated for the first time at the age of 12, when Lizzie required an inpatient hospitalization and Bella was still at home. It was at this time that we realized that the girls were each other's biggest triggers, as Bella's behaviors improved significantly while Lizzie was away. I realized that separating them in their own bedrooms would cut down on the fighting and the meltdowns. The only solution was to divide our family room in half (a sacrifice for the entire family), and move our son down to that makeshift bedroom, so that his bedroom could be given to one of the girls. This move actually did help to lessen the

escalations between Bella and Lizzie, yet once again, one of our neurotypical kiddos was suffering the consequences of his sisters' actions, which of course seemed totally unfair, especially in the eyes of a 14-year-old boy. Threats of violence from the twins towards other family members in the home happened often. Bella once tried to break down her older sister's door, stabbing it with a knife and threatening that she was going to kill her. This sibling is now 21 years old and is currently trying to work through her trauma with a therapist. It has been a difficult path to healing for her, as it continues to be for all of us in one way or another."

Jonas: "I tried to reach out to other parents for help or advice, but no one understood. Most parents told me that I was too soft of a parent, that I needed to be more rigid with Jonas, and that he needed more severe consequences for his actions. But other parents (including my own mother) told me that I was being too hard on him and that I needed to ease up and not be so strict with him. It was so defeating. I felt so alone. I saw the shaming looks in the grocery store. I sat through a verbal chastisement about how poor of a parent I was, when my son had a rage at a public park, and I had no vehicle to retreat to. It was isolating and heartbreaking."

Carson: "We struggle with friendships. Carson does not have many friends outside of school. We have almost no family support. Carson was adopted and we've even had a friend say, 'You signed up for this', when trying to get emotional support. This disease is very isolating. We are in a good space now, but Carson still appears to be disrespectful at times, and other parents can be judgmental."

Zack and Annie: "We were living in trauma and secret horror and felt that we had no understanding or empathy from those around us, not to mention, respite. In 2017, we went to

Sanibel Island, and we had a condo on the beach. It was idyllic but the rages came anyway, and I had to hold Zack down, bear hugging him, for almost two hours. The whole time, I was just hoping that the local police would not get called. We have felt the need to manage this on our own, for fear that asking for too much help, might get us helped right into jail or a foster situation. Zack's behaviors have alienated long-time friends and have prevented new friends from coming over to dinner. The loneliness of this diagnosis, and the extent to which one feels on their own, has extended from everyday life to vacation. There is no relief, no escaping it."

A Promising Protocol and Transformation

The community of parents whose children are diagnosed with DMDD is growing every day as noted from the tens of thousands of parents in online support groups who are desperate for connection and advice. It is common to read stories of rage, police interactions, hospitalizations, and desperation on a daily basis. Parents publicly lament when they have resorted to signing their children over to the state, because they have been unable to help or keep them safe. There is a common thread in the support groups, that despite the odds, there are children with DMDD who have reached long-term stability. Testimonies of a promising medication protocol started to emerge in these groups from parents who discovered the work by the now retired Pediatric Neuropsychiatrist Daniel Matthews M.D. In the 1970s, Dr. Matthews discovered a successful medication combination while working with impulsive, explosive, pathological juveniles residing at an inpatient facility. He found that these children had an electrical abnormality in the brain. After a rage episode, the child often could not recall what had happened. Dr. Matthews' findings led to a unique approach to treating DMDD: getting to the root of the brain abnormality with

anti-epileptic medications in conjunction with amantadine. For 20 years, Dr. Matthews teamed up with the late Neuropsychologist, Larry Fisher, Ph.D., and together created a unique plan that not only kept these children out of the hospital but helped them to thrive in society. In 2015, Dr. Fisher presented a lecture where he outlined how the dysfunction was happening inside the brain, and why this medication combination could be successful in treating this disorder. Numerous parents who stumbled onto Dr. Fisher's video felt as though it was the first time anyone had ever understood their child. Learning there could be a possible medication treatment to help, was the first sign of hope for these families. *Author's Note: Revolutionize DMDD, a 501 (c) (3) non-profit has obtained copyright of all of Dr. Daniel Matthews' documentation for the medication protocol upon his retirement. All related materials for families and medical professionals are available for free on the website: www.rdmdd.org.*

Julia: "In late 2018 or early 2019, we decided to try the protocol outlined by Dr. Daniel Matthews, starting with giving Julia the generic form of Trileptal. We started to see some improvement and then added amantadine about a month later. Her daily outbursts almost completely went away. She became so much less reactive and more in control of herself which was life changing. And when she did get upset, she was able to reflect and change course in a reasonable and age-appropriate way. She also became less irritable and able to get along with friends and peers. Meanwhile, the Trileptal helped calm her fears. During our state of crises, she was a mess on a nightly basis - afraid of terrorists attacking, people breaking into the house, people being mean to her, etc. She was paralyzed by these fears to the point where she truly couldn't function and would just cry until she fell asleep. With the Trileptal, she became much more reasonable and understood that her brain was playing tricks on her.

At school, she went from getting all ones and twos in the social/emotional measurements (on a scale from 1-4) to getting all fours by the fourth marking period in third grade. Her teacher was blown away by the transformation and said she felt like she was dealing with a completely different child. We saw the same improvements at home. The protocol has been life changing for us. She has been on it for five years and is now 13 years old and would be considered “stable”. She still suffers from anxiety and has needed added emotional support particularly through the puberty years, but she’s showing continued progress and we remain hopeful about her future and her ability to lead a normal, productive life.”

Carson: “We had a psychiatric evaluation that confirmed my suspicions of DMDD. After all of my internet research, I finally found out about the protocol developed by Dr. Daniel Matthews. I printed out everything I could and took it to the psychiatrist. Carson is now on the full protocol. He can be in school all day now. He says please and thank you. He says he loves us. He says he is sorry when he does something wrong. He is a much more rational thinker. He is easier to be around. He can laugh and joke and smiles voluntarily for pictures.”

Bella and Lizzie: “I had been hearing about the DMDD protocol developed by Dr. Matthews for a couple of years on the DMDD support Facebook page, but the girls’ providers weren’t familiar with it and therefore, weren’t interested in the documentation I could provide. We finally started with a provider in our area who knew a little about it and was willing to give it a try. At this time, we were planning a move across country to be nearer to a residential treatment center for Lizzie. Though this had been a heartbreaking decision for us to make, we felt like we had no other choice by that point. Miraculously, though, having started the girls on the protocol before the move, by the time we got to our new state, life was starting to have a

slightly different feel, a little less heavy. Although we were almost afraid to believe it at first, the medications were really starting to have a positive effect on the girls. We could see tangible differences in their behavior. They were not flipping their lids over every little thing, and their brains seemed much more regulated, even amidst newness and challenges from the move. The therapy clinic that we found in our new state was nothing short of a miracle in itself, as it also had a provider who was familiar with this protocol and continued to work with the girls.”

Ben: “His third hospitalization changed his life. Ben was sent almost seven hours away from home, as that was the only pediatric psychiatric hospital that had a bed for him. He was 12 years old and had raged for hours the day I made the decision to send him there. He had a particularly violent episode where he was placed in the seclusion room, and a team of 12 adults had to work together to physically restrain him so the doctor could sedate him. I made the heartbreaking decision to sign custody of him over to the state and place him in the state institution. I numbly filled out the paperwork and submitted it. I dove head-first into a deep depression as I wouldn’t be able to see my son’s beautiful face every morning. I wouldn’t get “Ben squeezes” or hugs when he needed some reassuring. I felt like I had failed as a parent and my son would grow up with the walls of a hospital and a nurse tending to him. I knew that there was something that doctors hadn’t figured out, I said for years that there was more going on to make him rage like he did, but I was dismissed by the psychiatric community, saying he was just a complex case. In those incredibly dark days before he was set to be transferred to the state institution, I collected all his records and started reading through years of treatment and observations. It was when I got to his testing results that I again read ‘DMDD,’ and realized I had never investigated it. I went to the only place I had at my disposal: the internet. I read through

research studies, blogs and anything I could find on DMDD. I couldn't believe what I had found, there were other families with kids just like Ben. Their stories were so close to ours; I knew that I had to dig deeper. I searched for medication interventions for DMDD and stumbled upon an article in "Psychiatric News" published on the 6th of April 2018, just months before Ben was hospitalized. The paragraphs contained therein would lead me to Dr. Daniel Matthews and his work. Then I got the call from the hospital that Ben would be transported in three days, and I needed to bring him what he would need and say my goodbyes as the institution was across the state and I didn't have the resources to visit often.

I collected his things, cutting drawstrings from shorts, and removing laces from shoes. And I kept digging into Dr Matthews' work. The night before I left, I found the videos that he and Dr. Fisher had on YouTube, and I saved them to listen to. The next day I started the seven-hour drive to my son, with the audio of those videos playing through my stereo. I listened intently to what the doctors said. I yelled and cried as they talked about DMDD and how the kids behave. It was like they were talking about Ben, not just a diagnosis. That night I was able to finally hold him, but only for around 40 minutes as he was so sedated, he couldn't stay awake. I returned to the hotel and watched the videos again, taking notes this time. The next day I met with his doctor and care team, I told them what I had found and tried to explain Dr Matthews' work. The doctor told me that it was time to give up. He said my son was a danger to himself, my family and society and needed to be locked in an institution and forgotten about. I slammed my hand on the table and yelled "I haven't tried everything! I haven't tried this!" I removed him against medical advice, rescinded his application to the institution and brought him home. I called Dr Matthews' clinic and requested any information that I could give his doctors at home. Three days later, with packet

in hand, Ben and I walked into the doctor's office. I begged his medication manager to start the protocol but was asked if I could give her time to research the medications. I agreed, and ten days later I received the call that she agreed to try them. Four months later my son was a completely different child.

Ben went from completely out of control to a seemingly neurotypical child. The behavioral problems at school and home stopped. He was finally happy! He went the next three months without a single incident at school. He could manage his frustrations without lashing out at anyone. He could walk past his brother without hitting him. Reports from his teachers started coming in: he was a delight, the most respectful kid they'd had in years, very responsive and helpful. He was completely changed. Today he is 16 and a junior in high school. It's been four years since he was stabilized on the protocol developed by Dr. Matthews and life couldn't be better. He was named captain of the JV basketball team this year. No one knows the 'DMDD side of him;' they've never seen it. His peers view him as an equal, and his teachers use him as an example for other students. The few people I've told of his diagnoses are flabbergasted and don't believe that he could be anything but the amazing young man he is now.

I wish I could have found Dr. Matthews' work at the beginning of our journey with DMDD, but I am forever grateful that I found it when I did. I had lost all hope that my son would ever live outside my home, but he now has a future and it's wonderful. He will graduate high school next year and will receive his certificate in welding. I know now that his behaviors were never intentional. His brain was not functioning correctly, and he didn't do anything out of hate. He couldn't control himself. So many people believe that this is intentional behavior, but it's not. The right medications can stabilize the brain and allow these kids to function alongside their

peers. They can and deserve to be happy and experience life in control of themselves. Ben has not had an outburst in four years.”

Jordan: “Through hours of advocating and researching for answers and treatments that might bring Jordan and our entire family some relief, I discovered the information about DMDD. Even as a licensed professional counselor, I had never heard of it or been trained in dealing with it. After watching the videos, reading the materials, and talking with some of his counselors, I decided to reach out to a doctor near us in a neighboring state to consider the possibility of the protocol. We were at a point of desperation, as my son was able to articulate that his thoughts about dying were at about an 8-9 every day (scaled 1-10). He was already on other medications for anxiety and depression that we could keep onboard while starting the protocol. He was taking a couple supplements, lowest dose of Pristiq, hydroxyzine as needed, and then started the Trileptal and amantadine. The first few days, he was incredibly tired. I feared we had made a wrong move. But then, rather quickly, we started seeing amazing results. Our son had been perpetually irritable, and instead, he now had a lighter and brighter demeanor. He had struggled with quick trigger frustration and explosive anger, and instead we started noticing his ability to tolerate things better and attempts to communicate. He was typically easily overstimulated with being outside, the breeze, others talking, smells, wind, rain, anything sensory related and yet I began to see him problem solve how to handle those elements and adjust. Chronic irritability was replaced with some ease and content. In fact, after going to town to run errands and eat out one day (which would have been a total disaster before), he casually remarked on our way home, ‘Wow, life is feeling really fun!’ WHAT?! He had never reported feeling that before. And nothing in this day had even been fun! He started using his words to express himself, his aggressiveness

disappeared, he had a brighter look in his eye, tolerated his siblings, and began showing more willingness to do things, interact, and take part in things even if they were new or unfamiliar. His angry, demeaning, insulting words totally stopped. It was truly miraculous!

After being on the medication for three weeks, I checked in with Jordan about his thoughts of harming himself or dying. He said the feelings had gone from an 8-9 to a 6. Within one more week, I check again on his thoughts of death or dying. He answered without a pause, “Mom, THEY ARE ALL GONE!” It gave me goosebumps then, and even now as I write it. Since adding the medication protocol to his other medications for anxiety and depression, he has not once struggled with his thoughts of harming himself, dying, or feeling like life would be better without him. He switched schools and reports, “I love school! And for the first time, I have friends!” He played football for the first time this year, and even had to start as quarterback one game! He ran for student council vice president and won! And he tried out for a part in the Christmas program and got it! This treatment, along with learning how to understand his body, his wiring, his needs, and what works best have turned things around for him. But it didn’t just affect him, it affected our whole family! It has also fueled my passion to help other families struggling on similar paths.”

Patrick: “One afternoon, I turned to Facebook and keyed in the letters ‘DMDD.’ To my surprise, there were other families out there with kids just like Patrick. I spent the evening watching videos by Dr. Matthews on YouTube where he described a treatment protocol for DMDD. Armed with this preliminary information, I made a special appointment with my son’s psychiatrist and insisted we give these new medications a try. He was hesitant. This wasn’t the traditional use of these medications, but he finally agreed to start the first medication, Trileptal.

Things stabilized slightly at home in the course of just a few weeks. We saw a calmer disposition and rages reduced to two or three times a week rather than daily. We titrated up, and eventually the doctor added the second medication, amantadine. Within three days, it was as though a fog had cleared from Patrick's eyes. He was agreeable, calm, and went rage free for nearly two weeks. Over the course of a few months, he had reduced rages to only twice a month, lasting only 30-45 minutes and reduced in intensity. School was going better too – and he was able to start making friends. He got invited on a playdate. Through information available about the protocol from Dr. Matthews, we learned that some children need a 48-hour break from amantadine for receptor exhaustion every so often. (The breaks were a chilling reminder of where we had been and how far we had come.) At nine years old, Patrick was what we call stable. He admittedly still had struggles, but it was nothing like the terror we previously faced on a daily basis.

Today, Patrick is mostly thriving. He still has some rough days, but they are likely the normal ups and downs for a pre-teen. He has found a friend group, attends normal summer camp and was voted to be a leader after giving an inspirational speech. He joined a travel lacrosse team, attends youth group, and serves at church. He still struggles to turn his work in and stay on task at school, but his IEP is providing new goals to help him meet the challenge of Middle School.”

Barry: “It’s been three years now since I saw a post about the treatment developed by Dr. Matthews by another parent whose son was being treated. I know deep in my bones that if we hadn’t learned about it, someone would have been seriously hurt and my son would be hospitalized or more likely, in jail. Today, he took Valentine’s presents to a girl at his high school that he has a crush on, and the rages and the constant irritability are just a blur. I can see how his

brain is growing and developing as his functionality improves. I will be honest and say that we have a long way to go with him and he has other very serious diagnoses, so we aren't the most dramatic testimony—but the peace in our house and our son's chance at a life still feel like miracles. My biggest hope now is that others can learn about this, as early as possible, and that through the treatment, kids with DMDD and their families will suffer so much less."

Jonas: "A Facebook support group led me to research the protocol developed by Dr. Matthews and it seemed very promising. Jonas was already on an anti-seizure medication (Lamictal), and it was doing exactly what Dr. Matthews said it was supposed to do! I brought the information to Jonas's psychiatrist and, fortunately, he was open to trying it, even though he did not know much about it. He liked the lower side effect/risk profile of the protocol drugs vs. antipsychotics or other mainstream treatments, and felt it was worth trying. We added amantadine to Jonas's medication regimen. It was amazing! The irritability decreased. Jonas started smiling and had times where he was clearly enjoying life.

Jonas is now about to turn 14. Some adjustments to his dosages were made after the onset of puberty to keep him stable. Jonas continues following the protocol as directed. Jonas is one of the approximately 25% of patients that needs an amantadine break for 48 hours every 3 weeks to combat receptor exhaustion. He is now a normal teenager who participates in the school robotics team at a prestigious charter school. He has a great group of friends. This year, the ever-present callous on Jonas's left knuckle (from where he continuously picks at the skin) finally started to heal. Just a few months ago, Jonas quit biting his nails for the first time since he was a toddler. This year, for the first time ever, there was no 'Christmas excitement rage' we used to expect. Ten years ago, I was so worried about Jonas's future. I was concerned he would

grow up to abuse his girlfriends, wives, and/or children. I was worried he would end up in jail. Now, I know Jonas has a good chance at a bright future. The protocol developed by Dr. Matthews changed our lives.”

Cid: “I asked my son’s psychiatrist to try the Dr. Matthews’ protocol, but he was reluctant. I switched doctors to one who was more familiar with the medications. It took about half a year to wean him off Latuda and onto Trileptal and then amantadine. And there were some episodes as we slowly weaned from his original medication. But it was so worth it! My son began to smile. He stopped getting angry when he couldn’t have what he wanted all the time. He stopped trying to jump out of the car on the way to school. He asked to join marching band as a freshman in high school. And best of all, I was no longer covered in bruises! It’s been two years now using this protocol and I don’t think we would have survived all our ordeals without it. Cid is 15 now. In the past two years he has also dealt with treatment of hypothyroidism, growth hormone deficiency, and a relapse of CRPS, which kept him in a wheelchair for half of 2022. He also has faced social isolation, racial bullying, and physical bullying at school. What he hasn’t done is lash out physically at his family when stressed, he hasn’t avoided school (despite his physical ailments), and he hasn’t threatened to self-harm. When Cid seems to have moments where I fear his stability is slipping, we pursue bloodwork to determine which meds to tweak to regain stability again. And to be fair, things aren’t perfect all the time. But I believe no child is – neurotypical or neurodiverse. He works hard on facing his fears and his physical pain head on. He goes to physical therapy and sees a physical trainer at the gym. He’s even applying for a weekend job! He’s practicing driving to get his license at the end of the summer, and he has goals post high school. He wants to go into the Airforce, and he wants to practice sports medicine

afterwards. And I truly believe he will be able to accomplish these goals because this protocol has given him this chance to succeed in life.”

Zack and Annie: “When I came across the protocol for DMDD by Dr. Matthews, I was skeptical, but knew that we had nothing to lose. People kept talking online about great success with this method, so I gathered the documentation and presented it to our physician. She told us not to ‘get our hopes up’ but said that she would be willing to try it since nothing else had helped Zach. After just a month or two, we saw that the Trileptal was improving mood, and adding amantadine sharply curbed the impulsivity and aggression. It was like a miracle.

However, a side effect problem ensued. My son, with a history of chronic migraines, started getting migraines related to the Trileptal increases. So, while he had a miraculous level of stability, we had to switch to one of the alternatives with a lower likelihood of causing headaches, Vimpat. Our local children's hospital had never used Vimpat in psychiatry, but luckily our doctor was willing to consult with the neurology department at the hospital, and consequently felt more confident trying it. And it worked! Vimpat, along with guanfacine ER, is keeping our son stable. Zack is back in school, takes some regular education classes, and has a few friends. He is still somewhat impulsive, but he is not angry anymore. He’s learning to play piano, showers every day, and keeps his room clean. We have occasional bad days, I think largely because of the autism and anxiety, but he is stable.

As Zack stabilized at age 13, 10-year-old Annie was rapidly regressing. She too would be diagnosed with DMDD. Our doctor started her on the same medication approach used to stabilize our son. It only took about four months before our daughter was miraculously stable.

Annie does great on the Trileptal and amantadine combo, and only experienced temporary side effect issues initially. The school called, commenting that they couldn't believe the changes they had witnessed! For our daughter, making sure she is at the target serum level of Trileptal has been important for her stability and we make little tweaks and adjustments as needed. We also have guanfacine ER onboard for ADHD and Lexapro for anxiety. We later had to add a stimulant for ADHD after mood stabilization, and this is helping with focus at school and for her, has not caused more irritability, even though it does for most. Annie was just admitted into a private school that required an entrance exam. She just celebrated her 14th birthday, inviting about 15 friends over. She volunteers at the library and is keeping her grades up for the most part. She is beautiful, artistic, hygienic, and social. She requires structure and support, but the difference has been incredible. She has even developed a positive relationship with her brother."

Kevin: "My son had been on a total of 23 medications over a 6-year period. He had 3 hospital stays including a 1.5 year stay in a residential facility and he was still not stable. We needed answers. I joined all the DMDD groups I could find online, and it led me to Dr. Daniel Matthews' protocol. Everyone was skeptical because nothing else had ever helped him. We had so many disappointments and terrifying side effects, including increased violence and suicidal ideation. This was our absolute last hope. In March of 2018, I found a medical provider willing to see us, but I had to pay out of pocket for his visits and travel 1.5 hours from home. In March 2018, we started slow and steady with the medications and endured increased behaviors during titration that we did not know at the time, could be expected for some. We powered through and in June of 2018 was the last time we had a violent episode. Age 5, or perhaps younger, to

age 11 were the worst years of our lives. Had my child not had our support and the support from amazing medical professionals, I know we would have had a very different outcome.

Today my child is 15 years old. He still has the possibility of having autism and we manage his anxiety and depression and additional medications. We have decreased the actual protocol medications as he has grown and still have had no violence since June of 2018.”

Eileen: “After Eileen’s hospital stay and her diagnoses of ADHD, Autism, and DMDD, I joined every parent support group on Facebook that I could find. I discovered the protocol developed by Dr. Matthews and Eileen started on Trileptal. Within a week, her mood changed. A few months later we added amantadine. Within 6 months, the rages slowed and then stopped. Occasionally, during puberty, we’d have breakthrough behaviors, but overall, we had become accustomed to the lack of violence in our home. Depression and anxiety began to emerge as rages subsided. Three years into treatment, we pulled her from amantadine due to lack of appetite that we couldn’t resolve. We continue to search for alternatives for her impulsivity. Still, what is known as the protocol developed by Dr. Matthews saved my child’s life. I recommend it to every DMDD parent.”

Jeffrey: “In February of 2022, Jeffrey was released from inpatient treatment. He had a doctor who was willing to give the protocol a try. The journey we endured while we got him to a therapeutic level was challenging. It got hard before we saw any difference in Jeffrey’s behaviors and we wondered if we had gone down the right path. Now, one year later, Jeffrey is stable and doing well. He is making straight As. He is in band, he loves animation, and shares his work on his YouTube channel. He is now able to identify some of his own triggers and is learning if it’s a

situation he can “handle” on his own or needs an adult's assistance. We've been several months without any rage incidents at home or school.”

Nathan: “The moment of biggest consequence for my son's development is when I discovered a recorded lecture by Dr. Larry Fisher, a neuropsychologist who was presenting to a group of behavioral health professionals in 2015 on the subject of DMDD. Somehow, Dr Fisher, from across the ocean and five years in the past, had described Nathan better than any professional clinician who had ever met him! After learning about the protocol developed by Dr. Matthews and watching Dr. Fisher's presentation videos explaining how it works, getting my son on these meds was my top priority. My son's psychiatrist was willing to prescribe the medications, and my wife listened and agreed with my reasoning. But everyone else I spoke to seemed to think it was mad. For me, part of that rational decision was assessing the risk of doing nothing. My son was raging multiple times every day, in almost constant distress and socially isolated. It also seemed to me that antipsychotics, which are now routinely prescribed for aggression in both DMDD and ASD, carry considerable side effect profiles including dyskinesia (physical tics) and large weight gain. And when I compared those side-effect profiles to the two medications in the protocol from Dr. Matthews, it seemed they were no more of a risk.

The NHS were simply unwilling to prescribe these meds as they were be considered 'off-license' ('off-label' in the US). I continue to this day to pay for them privately, even though our tax is supposed to fund universal health care. And the medication combination has stabilized my son, in a profound way. My son rarely rages any more. He went from raging 3 times per day to it being a rare occurrence. And in the rare moments where he does rage, they are shorter, and less intense. He is more open to dialogue and responds to suggestions for how to help calm himself.”

Kellan: “When we were discharged from my son’s first and only psychiatric ward hospitalization at age 6, the intake specialist said ‘you have my email when you need to come back. Just reach back out.’ I was stunned. Why did they assume we would need to come back? I was feeling hopeful, but it sounds like they knew something I didn’t. Did they know that the treatment my son had received might not work to stabilize him long term? It turns out, they were right. But luckily, for us, we learned about the protocol developed by Dr. Matthews. My son stabilized within 6 months on the protocol (while also successfully addressing his anxiety/depression and ADHD) and we never did go back! My son hasn’t had a meltdown in 5 years. When he was reevaluated, we were told “given his history, he is the most beautifully medicated child I have ever seen in my entire career.”

Michael: "When Michael was 10 yrs. he was released after two weeks from one of the top pediatric psychiatric hospitals (#3 in the country) and was no better. During that time, we discovered Dr. Fisher's presentation on DMDD. We watched in amazement because he was explaining our son! We then reached out to Dr. Matthews' office for more information. Thankfully, our psychiatrist agreed to consult with Dr. Matthews and try the protocol. That May, we started titrating Michael up on Trileptal (the brand because he had been allergic to the generic) as we titrated down lithium and Clonidine. Then, added amantadine. Three months later, right before the start of middle school, he was finally stable and happy. We requested a meeting with the school because he was different, and we wanted him to have a fresh start. After they observed him for two days, we had a meeting. The woman who did Michael's 20-page FBA/BIP the year before said this child is completely different from June. She went on to share how he now high-fives kids in the hallway. He's smiling now! You can have a conversation with

him, and he's funny. Before, he was anxious, would hide or try to stab someone with a pen. They were pleasantly stunned by the dramatic transformation. He even looked different as his hair was growing in naturally straight (lithium made it brittle and curly). Michael went from being isolated in a classroom to being integrated to mainstream classes. He went from two one-on-one shadows to only one that stayed in the distance. As the year progressed, Michael got involved with the school plays and even performed magic tricks in the talent show. A year to the day we started the protocol, we were attending a play. Michael was sitting next to me, singing, and kissing my hand while enjoying the show. In my heart I said thank you, Dr. Matthews. I have my son back."

Final Words from Parents

A few parents share their final thoughts, which echo the sentiments of many from the DMDD family community in the following quotes:

"The DSM-5 uses 'outburst' to characterize DMDD. Parents often use the word 'meltdown.' It seems clinicians prefer to say 'crisis' now. Whichever word is used, none of them clarify if the behavior is anger or whether it is rage. For parents of children with DMDD, the distinction matters greatly."

"As a childhood cancer survivor, I distinctly remember the day of my diagnosis. I was brought to the doctor, tests were run, we were ushered to a small room, and our lives were swept off the ground. Resources, treatment plans, respite/palliative care, were all at our fingertips. Mental illness is different. Instead of having a path to follow, we were questioned and told our son would grow out of it. Instead of getting a list of resources, we had to find them ourselves.

Instead of a firm treatment protocol, we spent years trying different medications that never really worked. Children with DMDD are missing out with the slow pace of diagnosis and treatment."

"I wish the protocol developed by Dr. Matthews would be studied further. I know the importance of peer-reviewed research, and this protocol should be in every book and article written about DMDD. This is a promising treatment, and doctors need to learn about its potential."

Concluding Thoughts

This chapter provides a glimpse into the everyday lives of children who have been diagnosed with DMDD. For most parents of children with DMDD, finding a diagnosis for their child and successful treatment is a long and lonely road. Parents battle their afflicted child's chronic irritability and fight or flight episodes at home, while teachers may endure an equal battle at school. The police and child protective services may be summoned, in some cases numerous times, to assist a DMDD child in crisis. Medical professionals struggle without a standard of care treatment for this disorder. Hospitals may admit the same children with DMDD year after year without seeing long-term stability.

The parents in this chapter have shared their family's DMDD journey hoping it will spark a much-needed change in how DMDD is recognized and treated. Parents, who have found long-term stability for their children, now pass the "torch" of what they have learned to those in the behavioral health community who have the power to implement an effective change to transform the lives of children with DMDD. Creating a road map for the future depends on what

we do today. For those families who have not yet found stability for their raging child, tomorrow cannot come soon enough.