



Empowering families.
Fighting Duchenne.

Dear Newly Diagnosed Family,

I still remember my heart stopping when I heard the nurse say that my son had a deletion of exons 8 to 27 which I knew was consistent with Duchenne.

I had been researching Duchenne and talking with medical friends for six weeks since his initial CK testing. At the beginning I could not believe that my happy just turned eight years old son who had played sports and was currently in karate could have Duchenne. As I learned more about the disease I had convinced myself that he likely had Duchenne or Beckers and devised a treatment plan but that was not enough to cushion the blow of hearing those words.

The next step was to share the diagnosis with my wife, children and parents. Each discussion felt like a loss and tore at our heartstrings. Telling friends and explaining Duchenne over and over was so difficult that we only told our closest friends. My wife Rana had discussions with her work colleagues while my focus was on communicating with other Duchenne families. We avoided public discussion of Duchenne on social media not wanting to have to explain it again.

All of this was difficult but our son was the same boy that he had always been. His abilities and needs were changing but he was otherwise the same. We learned that he saw that we would meet his needs the happier, more comfortable and better behaved that he would be. We learned from other Duchenne families, his doctors and patient organizations about his needs and treatment options. We talked with his school, implemented plans and provided equipment to help him as his needs changed. We talked with the teachers, nurses, coaches and administration about how he was changing and what he should or should not do.

Having the diagnosis helped us to understand his physical limitations. Soon after we began to understand how the lack of dystrophin in his brain was responsible for changes in how he learned and acted. For example sight-reading and resistance to change in planned activities. We soon began to discuss changes from normal or planned activities multiple times in advance of the activity. Overcoming his resistance to change has made life easier for all of us.

Research became my way of coping, finding hope and being able to sleep at night. There are dozens of potentially life changing treatments at various stages of development. That is far more development than ever before. The studies also are moving faster. The ability to create and test treatment candidates is increasing rapidly as is the level of investment and number of companies developing drugs for our sons. This development is not just in the US but all over the world. Quite simply our sons will have access to better medication than any generation before.

Speaking of the past I have met and communicated with men with Duchenne in their 30s and 40s. They often have jobs, degrees and families. Their lives are not what we once expected for our sons but they are enjoying and controlling their lives. I want more for my son but am grateful for what these men have accomplished and the example they have set.

Duchenne has changed my perspective on life. I have always placed a high value on quality of life and experiences. I have lost friends and relatives who appeared healthy at young ages. They lived with an expectation of living to old age often putting off enjoyment for the later that never came. Both before and after the diagnosis we have traveled as a family and taken opportunities to enrich our children's lives. Now that has become even more of a priority. While I am dedicated to the fight to heal my son I also want to make sure that we all enjoy as much of this life as we can. These do not have to be expensive acts. A go-cart ride, a special snack, going for a swim or to the park, fly a kite, fishing, a hike, whatever it may be find an opportunity to work a little more enjoyment into your days.

Duchenne feels like an emergency but in reality it is a long fight. There is no need for or benefit to panicking. It will seem like each medical step takes forever but please remember to make the most of these days.

While we may feel helpless that we can not heal our sons yet there are many things that we can do to help them. This is a list of some of the adaptations that my family made over the last two years as they became appropriate;

- Adjustable bed base – will make it easier to keep acid reflux at bay
- Bidet(s) – provide a clearer bottom with less work
- Congestion – stay on top of it, muscles are needed for coughing
- Connecting – form relationships with other Duchenne families, everyone will benefit
- Fiber – fruit, veggies and fiber supplements are important
- Firmer surfaces – firmer beds and furniture are easier to move around on and stand from.
- Folding chairs – buy the smallest ones, keep them in your vehicle
- Grab rails – place them where he can use them, especially in bathrooms
- Intercoms – Google Home and Alexa work well. They also can make phone calls.
- Lifting equipment – use mechanical advantage to make lifting easier for everyone
- Massage table – makes stretching easier for everyone
- Mobility devices – wagons, strollers, segways, scooters let him take the load off
- Proper seating – get those feet squarely touching the ground or on a footrest
- Stretching – you can do this at home and it will make your son feel so much better
- Swimming – have fun the in the pool, he will safely exercise a large variety of muscles
- Yoga pads – to make steps smaller or as footrests

Over the last two years I have seen my son grow significantly. I have seen early gains and later losses in function. I have seen him transition from walking full time to using devices for longer distance travel. But I also have seen him become happier and more comfortable. His self-confidence and perception of self-worth have improved greatly. He understood his physical limitations long before we did. As he has seen us adapt to support him he has become comfortable and relaxed in his life. He excels in school and in personal relationships.

I will finish, perhaps where I should have started, in order to take care of your son you have to take care of yourself and it is much easier as a team than on your own. Take time for yourself. If you are in a relationship take time for your relationship. If you are happy your son will be happier as well.

Sincerely,

Bruce Ward

Bruce Ward
Jett Foundation
Community Ambassador, Arkansas



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Dear Newly Diagnosed Family,

I volunteered to be a Community Ambassador with the Jett Foundation because the year following my son's diagnosis, was undoubtedly the most difficult year of my life. Although we endured extreme shock and heartache as a newly diagnosed family, the experience has also brought us newfound courage, compassion, and the deepest possible understanding of what is important in life. Despite our obstacles, we've learned to support each other, stay united as a family, and appreciate the precious moments we have together. I hope to share the positive lessons I've learned through our experience to support other families suffering from a recent Duchenne diagnosis.

Our son, Jordan, was diagnosed in December 2017 at age three and a half. At the time, I had never heard of Duchenne muscular dystrophy and in fact, following the call from our neurologist with the genetic testing results, I was forced to Google the disease in order to understand what we were up against. At the time, we had an eighteen-month-old daughter and I was six weeks pregnant with our third child, another boy. It was unclear whether our next child would be affected by the disease until I had reached the midway point of the pregnancy. I felt tremendous guilt, confusion, anger and of course, depression over the situation.

We attended a Jett Foundation Family Workshop in Hartford, Connecticut three weeks after our diagnosis, where we were provided a plethora of educational resources, support services, and treatments both in progress and on the horizon. Although it was overwhelming to take in, I knew that gaining knowledge about the disease was a step in the right direction during a very disheartening time. When I was feeling helpless, I felt comfort in knowing that I had control over my son's treatment plan and could devote my efforts to ensure that he is provided the best possible quality of life.

I've learned through the first year following our son's diagnosis, that taking action to aid Jordan alongside others in the same situation has allowed me to gain an awareness of my own inner strength and feel empowered. I've refocused my priorities and purpose in life to channel my energy towards this incredibly important cause. Challenges are inevitable in our situation, but there is a strong community dedicated to fighting this devastating disease and we're here to support you. The advances in medical treatment for Duchenne continue to grow and we will never give up hope for a cure for our boys.

With Heartfelt Regards,

Diana R. Johnson

Diana R. Johnson
Jett Foundation
Community Ambassador, Connecticut



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Dear Newly Diagnosed Family,

As I write this letter I put myself back in your shoes. My son, Aiden's, diagnosis was the worst day of my life. For many, myself included I had never heard of Duchenne Muscular Dystrophy. After that day it has never left my mind. It took me a bit to get to the point where I felt like I was ready to learn about the disease and what it meant for my family and son. There is no easy way to wrap your head around it as no one can be prepared for this type of news. However, my hope for you is that you will come to see that while no one would ever want this life you can still enjoy it, you can cherish the moments, and above all you have a community that offers a ton of support. Jett Foundation is here to help. You don't need to do this alone. I felt alone in the beginning. I didn't know there was a place to go. The various programs that Jett offers are designed to help families and children navigate this road. An organization who truly cares and where most of our team have a personal investment to our community and our children. If you ever need someone to vent to, someone to explain something to you, someone to be there when faced with various challenges, and just someone to have your back, you totally have it here.

My first encounter with Jett Foundation was about 3-years ago when I attended a Family workshop. There I met other families that were going through the same thing. We all have the same fears, the same obstacles, and an understanding of each other that is unmatched. The information presented included proper care, frequently asked questions, open discussion, and a message of togetherness and positivity that we all really need. There were scientist present to discuss the clinical trials, their progress, and how to enroll. After this workshop I reached out and was able to get connected with trial coordinators to ask questions. If it wasn't for this workshop I would have never known of all of the hope that is present in this world. My son started a trial last year and I know with out a doubt we wouldn't be enrolled if we hadn't received this valuable information at the workshop. I found strength in myself I didn't know I had, and now as a community ambassador I have a platform to speak my thoughts, give input, and have become proud of the difference I have made in the lives of others. If anything I hope you take away from this letter it's that you can do this. You will learn what you need to know, and you will become the advocate and strength your son needs. I know it seems impossible now but in time you will become a fighter, you will become an expert in Duchenne, and you will accomplish it all fueled by the love you have for your child.

Sincerely,

Jillian Moore-MacKenzie

Jillian Moore- MacKenzie
Jett Foundation
Community Ambassador, New Hampshire



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Dear Newly Diagnosed Family,

My name is Seph and I am currently 17 ½ and am living a very full life with Duchenne. I am sorry that you are now a part of this family, but in that same regard, I welcome you.

Duchenne is not a death sentence with a child that stays at home all the time and plays video games alone. When I was younger, I was able to play T-ball, soccer at church events, ride a bike and swim like a fish. Although I was slower than everyone, I was able to play with them and make friends. Some of which I still have today.

I am also very good at school, currently taking three advanced placement classes and usually have a high GPA. In middle school, I was involved in choir and had the honor to travel to Utah to the National Middle School Boys Honor Choir. Around that same time, I did an amazing Make A Wish trip to Seattle, WA to the headquarters of Microsoft. While DMD is not a path I would choose for anyone, it has allowed me the opportunity to do things and meet people that I would never have gotten to do otherwise.

Currently, I am in High School in Virginia. I participate in the high school marching band, National Honor Society, theater class and forensics club. I have my driver's learning permit and will hopefully get my license soon. I love music; I sing, play the keyboards, ukulele and am learning the bell kit. This past summer, my mom and I were fortunate enough to go to Hawaii and I was able to see dolphins and swim in the Pacific Ocean. We believe where there is a will, there is a way! We are working on a trip to Japan now and then off to college to study architecture!!!

I have achieved all of this by having a good work ethic, instilled by my parents, and being told I can do anything I want; I just may have to do it differently. To have a good life with DMD, it begins with you, the parent. You have two options as I see it; Let your child become a victim, or tell them you aren't a victim, society can and will love you, and you can do whatever you want, nothing should or can hold you back. I think these lessons that my parents taught me have helped me be a successful young man with DMD. One thing my mom heard from a more experienced DMD dad when I was young was that he never wanted his son to say, "why didn't you let me do something, when I could." My parents, with caution of course, have always done this. I think because of this I attempt to figure out how to overcome most obstacles that I want to.

You are entering this journey at a great time. There is so much research going on, that I believe and hope that by the time your child is my age DMD will have a significant treatment and hopefully a cure.

I would encourage you to try to find great doctors for your child, answer questions honestly as they come, rely on this community for support and advise, and finally, if and when possible, help your child meet others with DMD. When I am with my Duchenne family is when I feel most at home. Good luck to you and your family!

Live Long and Prosper!

Seph Ware