

VOLUME 1
ISSUE 1

A MAGAZINE BY TEENS, FOR TEENS & ABOUT TEENS WITH DMU

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A LETTER TO
MY TEENAGE
SELF

THE
BIGGEST
POTENTIAL
IN YOU
IS YOUR
QUEENLY
POWER

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*I'm not looking for a
knight in shining armor.
I have my own set.*



WARRIOR

By
Delaney Van Riper*

From birth, I had multiple illnesses: asthma, ear infections, ringworm, colds, croup, scrapes and bruises. If only I had known what was in store for me.

At the age of 6, I started to fall more than usual. The first thought was that I was growing. Second was that I was a clumsy child. Third was that there was something wrong. After my father noticed I was walking on my toes a lot, I got tested.

I was diagnosed with Charcot-Marie-Tooth (CMT) at the age of 7. This meant multiple doctors' visits, an MRI, physical therapy and needle poking. I was in the second grade. I remember being told that I would either have braces or casts on my feet. As a child, this was exciting and something new; I was different. I didn't take into account the "rest of my life" part and the fact that there is no cure for CMT. I kept my spirits up by telling myself that I was unique. This lasted several years, until the hormones and insecurities kicked in.

At the age of 12, the looks and the questioning glances of "What is wrong with her?" started. Circulating in my mind like a merry-go-round were "those" questions: Is there something wrong with me? Will anyone love me? Could anyone love me? Who would want to date a cripple? Why me? Why?

Seventh and eighth grade were the worst years. Not only was I surrounded by stupid preteens high on hormones and pheromones, but CMT attacked my once-unaffected hands. I was depressed. I was grieving. I had lost a basic human function. No longer could I hold a pencil right. No longer could I snap my fingers. No longer could I pick up items like coins and paper from a flat surface.

At this point, CMT was in the back of my mind whenever I tried something new, nagging me with thoughts of how to adapt and still look normal doing it. I got angry, frustrated, and destructive, mainly toward myself. CMT had taken over my life and I was done. I wanted to stop everything—the doctors' appointments, the exercises, the expectations, even myself. To cope, I blocked off anyone and developed invisible scars. But somehow I carried on.

Eventually my parents' worry overwhelmed them and they confronted me. I opened up mainly to my mom, who had beat depression as a teenager. I remember one bad day when I saw my mom and I went up to her and hugged her. I started crying. She held me together while I broke. When I was ready we talked. I clearly remember her telling me how my sister admitted that she couldn't have handled what I have to deal with and my mom telling me how strong I was and wondering how I did it. I had no answer other than "It's what I do."

I've not yet won my war. I'm not looking for a knight in shining armor. I have my own set. It's not shiny. It's rusted and bent. It's been through terrible bouts and I am proud of my battle scars. I am repairing myself. I can feel when the bad days are coming and I prepare. I survive my struggles because I have done so for 10 years. Each day for 10 years, I woke up and got out of bed. Why not try for 10 more? I know I can do this. I know where the liquor, the pills and the razors are and I'm still here. I believe in myself.

* Delaney (Laney) Van Riper, 16, played recreational soccer from the ages of 5 to 13, and she began tumbling classes at age 12. Now that she's 16, she is able to do several back handsprings in a row and is working on her backward tuck (with ankle supports and occasional bruises). Delaney, from Sacramento, California, worked full time last summer babysitting triplets. She is considering being a creative writer as her profession. Delaney's CMT was spontaneous: It doesn't run in either parent's family. Ironically, her father is a genetic counselor.





CMTA
EDITION

⚠️ **WARNING:**
CHOKING HAZARD - Small Parts.
Not for children under 3 years.

POWER UP WITH
LITHIUM-ION BATTERY
NOT INCLUDED
PUISSANCE EN HAUT AVEC
BATTERIE AU LITHIUM-ION
NON INCLUSE

X2 ALKALINE BATTERIES
REQUIRED
FICHES ALCALES
REQUISES
ADULT ASSEMBLY
REQUIRED
DOIT ÊTRE ASSEMBLÉ
PAR UN ADULTE

OPERATION

Surgery

By Jacob Ortiz*

"You need surgery on your hip." When you are 10 years old, these words can be terrifying. I had so many questions, starting with "What is surgery?" After many visits to the doctor to figure out what was causing my hip pain, an orthopedic surgeon finally found the problem. I had hip dysplasia on my right side, caused by a hereditary neuropathy called Charcot-Marie-Tooth (CMT) that came from my dad's side of the family.

Ever since I can remember, I've been teased because of my disabilities. I was what people would call "clumsy." I dreaded going to P.E., not because I didn't like being active, but because it made me feel different. I wanted to keep up with my classmates so badly, but I always fell short. I had trouble with tasks like running, jumping or

just walking in general. This often frustrated my teachers and coaches because they assumed I was lazy. They had no idea how hard I was really trying. Even my parents thought I just needed to exercise more and learn how to run. My mom would run with me and try to coach me on "running right."

The worst part of being diagnosed with CMT was finding out that it is incurable. I was devastated. While my parents reviewed my X-rays with the orthopedic surgeon, I listened and tried to understand what he was saying. As they were discussing possible solutions, I started to get worried. It wasn't until they said the word surgery that I got really anxious. I wanted to interrupt them, but I was too afraid to speak up or say anything.

The surgery didn't happen right away and after a few months I began to hope that the doctor was wrong about me needing it. However, the pain in my right hip grew worse and worse. Just walking became unbearable. Eventually, my pain forced me to face reality. I went on a three-day camping trip with my fifth-grade class. On the second day,



we went on a hike. After about an hour, my pain started getting worse and I began falling behind. The group was getting farther and farther away and no matter how hard I tried, I just couldn't keep up. There were several adults in the group, but no one noticed how far behind I was. No one even turned around to look. Before I knew it, I was alone. I kept following the path and praying that I would not fall or get left behind. It took everything in me to keep my body from giving out. The pain was excruciating. I began to run as fast as I could. I caught up with the group just as they were loading up to leave.

My pain grew still worse during a family vacation to several amusement parks, starting with a two-day

trip to

Disneyland. The walks were torture and by the end of the day I couldn't keep up. We were trying to make our way up to Space Mountain but I just couldn't do it. We stopped at a bench and my parents discussed going back to the hotel. My mom looked at me and said. "Jacob, you're going to have to get that surgery soon." Hearing those words sent me into a panic all over again.

When we got home, my parents took me to the orthopedic surgeon. After another X-ray, he told us that my cartilage was completely destroyed and that my hip bone was breaking down. My hip now needed complete reconstruction. I tried to not think about it too much, but the thought of getting cut open kept creeping into my mind. During the week of the surgery everybody kept asking me about how I felt or if I was scared. The day before the surgery, I couldn't sleep. My mind was filled with frightening thoughts that I tried hard to push away. I had to be at the hospital at six in the morning, so I got little to no sleep that night.

Once we arrived at the hospital, everything happened very quickly. I checked in, got prepped and before I knew it, I was talking to the nurse who was going to put me under anesthesia.

She explained the process and how I would feel, trying not to scare me. Soon after, she had me count down and the next thing I knew, the surgery was over. I woke up in a hospital bed surrounded by my family. I felt terrible. I had wires attached everywhere and the medication made me really drowsy. The scariest part was that I could not move my legs at all. I was terrified that the paralysis might be permanent. Visitors came and went, but I did not feel like talking to people. I felt defeated. I just wanted to go home and get back to my life.

The day I was released from the hospital, a nurse came to my room to teach me how to get in and out of the wheelchair. It was so much harder than I thought it would be. Trying to get in the car was also hard, not just for me but for my parents, who were trying hard not to hurt me. I couldn't take the pressure anymore and broke down. After getting myself together, I finally made it home. However my struggles were not over.

I hated not being able to feel my leg. It seemed like I was never going to be able to walk again, but I kept those thoughts to myself. After a few months, I started to regain feeling. I pushed through my therapy. My mom had me do extra exercises at home and I saw myself improving more and more everyday. After that, I knew I was going to be okay. I pushed myself to my limits and I began to feel confident again. After about eight months, I was walking. It felt great to be able to feel and use my leg again. I'll never forget the first time I ran after my surgery. I felt free; I was free!

*Jacob Ortiz 14, is a committed student who enjoys spending time with his little brother, playing the guitar and learning new music. He never commits to something that he does not intend to finish and always finds a way to persevere despite his physical limitations.



A Letter to My Teenage Self

By Bethany Meloche*



Dear Me,

I am writing you from the year 2016. Before you get too excited, no, we do not all get around via jet packs and hover boards and you should still get your driver's license (spoiler alert: you may want to practice driving on both sides of the road). But in the brief time I have with you, Younger Me, I do want to impart some important tidbits of wisdom:

Stop worrying about what other people think of you. It is OK if people see your leg braces. It is OK that you walk differently than most of your peers. It is OK that you move slower. I promise, it is all OK. Most people are too busy worrying about themselves, their lives and their own insecurities to notice the things that you worry about. If they notice, they generally don't care. And ultimately, the things passersby in your life may or not think of you do not matter. When you stay hidden inside, you are the one who suffers because you're missing out on living your life to its fullest. I know, of course, that this is easier said than done. But trust me that life is so much better once you stop caring what other people think, and just live.

It's OK to ask for help. If your class decides that it would be so much more fun to eat lunch outside that day, on the grass (this phenomenon still perplexes me), don't slip away and eat lunch alone and miserable because you can't get up from the ground by yourself. Try this instead: Approach your least-intimidating classmate and say "Hey, my legs don't work that well. Do you think someone could bring out a

chair for me?" Boom. Done. Seriously, not only will the response be "Oh sure! Of course!" followed by someone hurriedly getting you a chair, but by you owning it and asking for help, people will actually respect and be drawn to you more.

Exercise and take care of yourself. It doesn't always feel this way, but you are in the driver's seat of your body. Not CMT. Do us both a huge favor and start taking control now. That means actually doing the exercises your physical therapists give you. Keep your core strong. Start cooking and learning to eat better. Don't keep putting on extra weight; it's a real pain for you to lose later. (By the way, you're allergic to oranges. You're welcome.)

Enjoy this time, but these are not the best years of your life. Yeah, that's right. I know it's hard hearing other people say how these years ARE the best days of your life, especially when you're struggling. They aren't for you. That's OK. They don't have to be. I have a sneak peek into your future because, well, I am your future. It gets better. No CMT doesn't get better, but you do. Surgery lets you walk again. Eating healthy gets you in better shape. I know it feels like your life is over, like your future is crashing in around you. It isn't. It gets better and better from here! So rest in the fact that your current problems will be fleeting (OK, I hear you saying "The CMT isn't fleeting," and that's true, but you will learn how to deal with that better), but still try to enjoy this time while you're there.

You can be the person you want to be. Right now you dream about the person you would be if you didn't have CMT. Adventurous. Risk-taking. Successful. Confident. YOU CAN STILL BE THAT PERSON. Sure, your adventures may look slightly different than if you didn't have CMT, but they will still be as crazy, adrenaline-rushing, mindblowingly inspiring and fulfilling. Trust me, Younger Me, it's going to be great. I'd tell you more, but, well, spoilers.

Love,
You

*Bethany, who has CMT1A, got involved with the CMTA as a volunteer when she was 18 years old. She is now 24 and the CMTA's social media director. She currently lives in London, England, with her husband Josh. She is writing to her 15-year-old self.



Focusing on the Positive

By Devin Miller*



My name is Devin Miller and I first started to feel the effects of Charcot-Marie-Tooth disease at age 11. Until then, I was an extremely active kid who loved wrestling. As I aged, I slowed down athletically compared to other kids because of a growing lack of balance. I quit the sport for a couple of years because I was upset that I couldn't perform the way I was expected to. At the time, I didn't understand what was happening to me. I got a job because I thought that my sports career was over.

After working for a couple of years, I got back into wrestling. I knew that I wouldn't be close to the caliber that I once was, but I still wanted to do it to show that I wasn't going to allow CMT to get me down. I came out and did a complete season in my freshman year of high school to prove to myself that I could do whatever I set my mind to. Although I live with a difficult disease, I proved that I was in control, not it.

The most valuable lesson I've learned from having CMT is not to let it get me down or prevent me from doing things. This determination fueled me into choosing pre-med as my college major. I want to help others find ways to live easier with their problems because I know how difficult some obstacles can be to overcome. I've learned to work harder as well as apply more effort if I want to do the same things as everyone else. CMT has taught me to become a hardworking individual and has given me the drive to never quit. Since I've learned to work harder in everyday life from having this disease, it allows me to carry those aspects to other parts of my life.

This determination also made me an entrepreneur. I have a new idea that I hope will make an impact on conservation efforts and cleaning efforts around the world. I don't really want to give my idea away since I plan on debuting my product this year. It's a new spin on an old appliance that allows it to be used more conveniently anywhere, perfect for college dorms as well as camping and even tailgating.

I'm also in the process of starting a CMT Awareness Club at Penn State where we will spread awareness as well as fundraise for the CMTA! I have a lot of things planned and I hope we will be successful!

Although I am affected by CMT, I have learned not to let it slow me down or make my life decisions for me. I've also learned to be thankful to God. I make the best of my situation because I'm blessed. Even though I have my complications, there is always someone worse and I am thankful for what I still can do. Life becomes easier and more bearable when you focus on the positives.

*Dev Miller, 19, is a sophomore at Penn State.



Youth Will Out: Leaving Patient/Family Conferences

A few years ago, the folks at the CMTA noticed that many young people were attending the CMTA's Patient/Family Conferences. They also noticed that the conferences didn't provide the right environment for those young people to connect or to share their experiences with CMT. CMTOutings were born. The concept was simple: After the science and speakers and table sitting of the conference were over, teens would gather, jump (or walk slowly) into a van and head out into the city for an evening of activity and fun. The concept was simple, but the results have been complex and wonderful. In the last few years, CMTeens have gone on outings in Chicago, Los Angeles, San Francisco, Orlando, Boston, and Nashville! They have eaten together, bowled, gone to Disney World, quacked through a duck boat tour, escaped from "The Escape Game," and so much more. Participants share a common understanding of what it's like to deal with differences, to face challenges every day and to manage the array of reactions from their peers, some for the very first time. We hope you enjoy these participant accounts of the outings—and that you'll be a participant yourself someday soon. The next chance will be June 4 in State College, Pennsylvania.





BOSTON CMTEEN OUTING: **Quacking Through History**

*By Annie Zanchelli**

CMT Teens kicked off CMT Awareness Month a little early last year, taking to the streets of Boston in an “Aquaduck” following the August 29, 2015, Patient/Family Conference in Bean Town. While the historic city offers many exciting activities, finding a fun and CMT accessible activity can be a challenge. Our fearless leaders succeeded in a big way.

Excitement and acceptance were in the air as the conference drew to a close. We all said goodbye to our parents and guardians and were put into the best possible (although “slightly weak”) hands of Jonah Berger and Bethany Meloche for the next four hours. All 15 of us held onto one another for support in the parking garage before hopping into a van to travel to the Aquaduck tour departure center.

An Aquaduck is a replica of a WWII type of boat that also works as a bus. The bus took us to a number of Boston sights, including the homes of Secretary of State John Kerry and President John F. Kennedy, some of the oldest parks in the country, and the sites where many famous Revolutionary War battles (such as Bunker Hill) took place. Then the bus turned into a boat, and we went sailing into the Charles River to explore more of the historic city of Boston. Our driver and captain introduced himself as “Almost Educated Aaron” because he attended Harvard ... for three days, then Boston College for one day... then Northeastern for one day, and kept moving to 359 colleges. Aaron gave us a chance to drive the boat, and three of us took it! After the tour was over, we gave each other an exceptional amount of support as we went two by two on the scary 8-foot- high lift to get off the vehicle.

Our group of teens and two pizza-hungry chaperones were excited to get to the California Pizza Kitchen afterward. This was more than a meal, though. It was also a chance to talk through the tough situations we all encounter on a daily basis. As young people we found our situations very similar: We get stared at, sometimes laughed at, babied, and have to persevere to find ways to participate. The consensus was, “We don’t let CMT control us, but it is a big part of our lives that we should embrace!” Or, as Jonah said, “Even though we have common issues, we all persevere.”

Boston isn’t the easiest city to navigate, and going across the bridge four times to find our location ended up being everyone’s favorite part of the night. As we departed from an amazing evening, Julia Beron advised everyone to “Be a Star!” It’s the best thing we can be through our mission to educate others about Charcot-Marie Tooth. So let’s all take Julia’s advice, and make every month CMT Awareness Month!

*Annie Zanchelli, 18, is a freshman at Columbia-Greene Community College and has CMT1A.



Nashville CMTeen Outing Provides Escape from Fears and Worries

By Payton Rule*

*To “escape” the rooms,
you have to find clues and
solve puzzles*



I recently had the pleasure of attending the CMTA Patient/Family conference in Nashville, Tennessee. Although I thoroughly enjoyed hearing about the latest updates on research and other developments at the conference, the highlight of the weekend was the CMTeen outing afterwards.

The outing was an opportunity for younger CMTA members attending the conference to hang out together for a night out in Nashville. Led by our awesome, fun and (a little crazy) chaperones Jonah Berger and Bethany Meloche, we participated in the Escape Game—a game in which you are locked in a series of rooms. To “escape” the rooms, you have to find clues and solve puzzles before your time runs out. While we didn’t escape in time, we had a lot of fun working together trying.

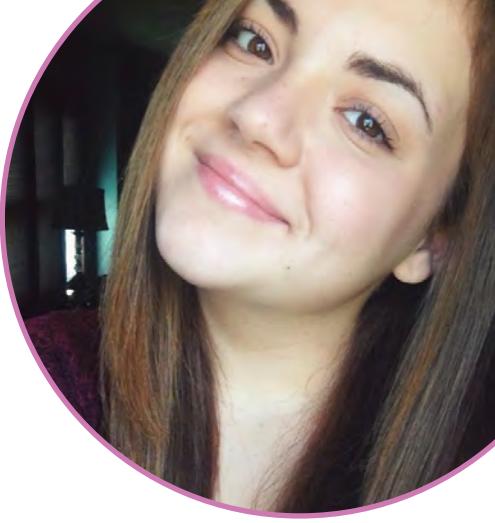
After the escape game it was off to dinner and a chance to kick back and talk. Being the only one with CMT in my family, I loved being able to talk to other people who share my struggles and understand the joys and hardships of living with this disease. Lots of funny CMT stories were told. I don’t remember the last time I laughed as much as I did on this night.

This was my second youth outing and I wish I could do more. Hanging out with other teens with CMT is not only a ton of fun, but it is also a huge relief. When I’m with my friends at home, I always have to worry about whether I can keep up or traverse the landscape we’re traveling through. Will there be stairs, hills or uneven ground? The youth outings have been one of the few places I can let that go. Everyone has the same fears, concerns and limitations. I know I’m not going to be left behind or struggling to keep up. It’s like the world is a different place. So, even though we didn’t escape the Escape Game, we did escape our fears and worries for an evening.

I’m looking forward to the next youth outing and can’t wait to meet and hang out with more of my fellow CMTeens. Until then stay strong.

*Payton Rule, 17, lives in St. Louis, Missouri. She has loved sports from a young age. Her favorites include snow skiing, basketball, and adaptive track and field. Payton also enjoys swimming and teaches swimming lessons to kids with special needs. Through her experience with CMT, Payton has developed a love for medicine and molecular biology. She hopes to become a neurologist so she can help others with neuromuscular disease. Payton is the only one in her family with CMT 2E.





CMTeen Nashville: Take Two

*By Savannah Shelton**

The CMTeen outing after the Patient/Family Conference in Nashville gave me my first opportunity to meet other teens with the same struggles I have. We went to the Nashville Escape Room, where we were locked in a room together for an hour and had to try to escape by solving different puzzles. This might sound easy—until CMT is added to the mix. You can only imagine all of us trying to pick up ping pong balls, opening small locks, and connecting small objects such as monkeys in a barrel. I felt like I wasn't doing things quickly enough, and became extremely overwhelmed at trying to accomplish so many tasks in such a short time. But the fact that everyone in our group shared and understood my struggle made everything easier. We went to dinner after the games and talked about our night, shared our CMT stories and also our own perspectives of living with CMT. We all realized the ups and downs of having CMT can be hard, but also a good thing. During dinner I felt like I didn't have to hide my disability: I could be myself and feel comfortable. Overall, the CMTeen outing was an amazing experience to connect with others who understand me and will help me get through what lies ahead.

*Savannah Shelton is a 14-year-old freshman honor student in the small town of Alexandria, Indiana. She is the oldest of three siblings in her family. She is involved in church, babysitting, and being a basketball manager. She spends her free time immersed in reading, writing, cooking, listening to music, and watching Netflix. She aspires to become a lawyer and then eventually a judge.

*You can only imagine all of us
trying to pick up ping pong balls*



The Potato, the Egg and the Beauty Queen

*By Jenna Williamson**

I was diagnosed with CMT when I was very young—between the ages of 2 and 3. As we all know, CMT produces challenges in day-to-day activities like running, jumping and dancing. I learned at a very young age to work hard and not give up. I might not have conquered everything I tried, but I always tried my hardest and learned to keep going. I play volleyball on my middle school team and I love to play the piano. Of course, controlling my over-flexible fingers sometimes can be a challenge.

When I was 6 years old, I attended the Miss Texas pageant. My dream immediately became to be on the “big stage” one day. Competing in a pageant has so many parts to it. I wanted to do what I saw the older girls doing: I wanted to have a talent, I wanted to speak in front of a crowd, I wanted to be confident and I wanted to walk with grace and poise.

Having CMT always produces obstacles, but those obstacles actually motivated me even more. I’ve never given up; I JUST HAD TO WORK HARDER. My parents have always told me, the harder you work, the more you will appreciate your success!

Being diagnosed with any type of disease or illness is scary and makes you worry about your future. I was the very same way. But I have learned and truly

believe in my heart that CMT is a gift that I have been blessed with. It has MOTIVATED me to pursue my dreams and it has given me a voice to help others stay strong and motivated! I may have limitations at times, but I have a fighting spirit and a positive attitude - and THAT is hard to beat!

On December 12, 2015, I was blessed to win a preliminary title and realize my dream! I won the 2016 Miss Hunt County’s Outstanding Teen award! In July 2016, I will be competing with approximately 45 other teens from the great state of Texas.

Every day I wake up and stretch my muscles and concentrate when my high arched feet hit the ground. I wouldn’t have it any other way. CMT does not define who I am. Actually, it has shaped me to be a better person, show others more compassion and work 10 times harder. The screensaver on my phone is a quote I read recently: The same boiling water that softens the potato, hardens the egg. It’s about what **YOU ARE MADE OF**, not the circumstances.

Wish me luck in July 2016!

*Jenna Williamson, 13, from Texarkana, Texas, is not just beautiful on the outside she's beautiful on the inside! How do we know? Part of her platform for the Miss Texas Outstanding Teen pageant is raising funds for the CMTA. You can find her fundraising page at: www.cmtausa.org/donate/jenna-williamson-fundraiser-for-cmta-organization





FLY Away... and help us make CMT go away!

Help the CMTA soar to new heights by fundraising for STAR research. It's simple and easy. Just raise \$1,000 and you and your friends can soar like eagles with an indoor skydiving experience.

For more information contact:
[Ori Bash](mailto:Ori.Bash@cmtausa.org) at ori@cmtausa.org

writers
wanted

Like what you've read in the first issue of CMTeen? How about writing something for it? We're looking for articles on anything that interests you—from braces to bullying to smart comebacks for starers. Please send submissions or ideas to marcia@cmtausa.org.