

VOLUME 2 ISSUE 1

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

CMTTeen

CMTA Dolphin Odyssey...

It's a whale of a tale!

The Cupid Shuffle!

Dog Day Afternoon!

Lucky Strike!

Training Camp...

Battling CMT!



Swimming with Dolphins, Finding New Friends

*By Erin Black**

Before March 18, I had never met anyone else like me. Meaning, I had never met anyone who wears big chunky braces, falls down and faces the other terrible and unique challenges of CMT. Swimming with the dolphins at the Miami Seaquarium was great, but meeting other people who share my disease was even better.

My adventure began in January. I was scrolling through my social media feed when I stumbled across a beautiful picture of palm trees posted by the Charcot-Marie-Tooth Association (CMTA). I was immediately interested, warm weather and the CMTA being two of my favorite things. The post was about a CMTA Patient/Family Conference in Miami. Reading through all the information, I soon realized how badly I wanted to be there. Unfortunately, I am only 15 years old, with not much of a budget. My wonderful family, including my amazing Aunt Peggy, agreed to help me get there.

On the day of the Dolphin Odyssey, my family dropped me off in the hotel lobby, where I met a group of 15 kids and chaperones. We started off as strangers. The only thing I really knew about these kids was that they were around my age, lived in many different places and, most significantly, had CMT. We hopped (or should I say slowly helped each other) into a big van and headed toward the Miami Seaquarium. We were warmly welcomed and ate lunch while learning about each other. The conversation flowed surprisingly well: When I mentioned physical therapy to the table, everyone moaned and groaned. That is when I realized, “These are my people.”

After seeing several exhibits and a whale show, it was time to meet the dolphins. We changed into wetsuits for the swim. Taking off our braces and getting into the cold pool water was hard for almost all of us. That is the amazing part: I was not alone for once in my life. It was okay to struggle because everyone else was struggling too, so we just helped each other and had fun doing it. After we changed, we got in the water with the dolphins. Swimming with these crazy adorable, yet extremely intimidating, creatures was incredible. We kissed them, shook their flippers, splashed and played. Just being in the presence of the 400-pound dolphins was wonderful.

After spending time with the dolphins, we changed into dry clothes and headed for a luau-themed beach party. On our way, we talked about the perks and struggles of living with CMT. One of the chaperones asked us each to talk about the best thing about having CMT. To be honest, I had never thought about it before. I said that overall, CMT makes me stronger, makes me the person I am and makes me realize how blessed I am to have such amazing friends and family. Finishing the night off at our luau was the perfect end to a perfect day. We drank mocktails (non-alcoholic cocktails) by the ocean and ate what I like to call “fancy kid food.”

It is hard for me to put into words what the day meant. We all started as awkward acquaintances and ended the night as unique friends. I even met my online friend Julia for the first time. She wasn’t the only friend I made. In just 10 hours, we all became friends. To see and hear how CMT affects all these amazing kids made me feel grateful and appreciate what I have. The chaperones with CMT inspired me to get involved and reminded me that this disease should not and will not define me.



***Erin, 15, lives in Cleveland, Ohio**

[Editor’s note: A lucky group of CMTeens recently had a day they’ll never forget swimming with the dolphins at the Miami Seaquarium. Erin Black and Maddie Leard share their unique perspectives on the day. A big-thank you to the wonderful folks at the Dralla Foundation, which funded the adventure.]



Swimming with Dolphins an “Amazing Experience”

*By Maddie Leard**



The CMTeen outing in Miami, Florida, was an incredible experience for everyone involved. The day started with getting to know each other in the lobby of the hotel. Once we got to the Miami Seaquarium, we helped each other walk to the spot where we ate lunch.

After a delicious hot dog and chips, we went to a whale show. At the whale show we didn't want to walk up the stairs for a seat, so we sat in the first row in the splash zone! We all got soaked by a huge killer whale's splash!

We dried off in the Florida sun as we walked around and saw other animals from penguins to stingrays. Then the best part of the day came: the dolphin swim. We squeezed into wetsuits and took off our shoes and leg braces, then jumped in to pet the dolphins, watch them do tricks, shake their flippers, and even kiss them! We were able to see them up close and personal and feel how strong they actually are even though they seem like such delicate creatures. We all bonded through that amazing experience, but there was more. We got to meet a dolphin with scoliosis, Luna. It was inspiring to see a dolphin work hard to overcome a disability and try hard to jump out of the water and do the best she could. Luna reminded us all that even though we have a disability, we can still do what others do even though we might not be the best.

After all that fun we were tired, but the night was not over yet. We changed into our luau attire and took a van to a breathtaking beach party. There were hamburgers and chicken kabobs, a D.J. playing music and even an ice cream bar with the most amazing toppings. When the night was over, we had all made some incredible friends who will always understand what we mean when we say “my legs hurt.”

***Maddie, 13, lives in Houston.**

Me and My Service Dog

*By Payton Rule**

*Payton, 18, is a high school senior and the co-leader—with her mother—of the St. Louis CMTA Branch. She will be taking a gap year after graduation so she and Whitt can bond and she can get training in working with him, then the two of them will head off to college.

After three years of waiting, I recently welcomed a handsome, tennis-ball-loving, 3-year-old Golden Retriever named Whitt into my family. Whitt was trained by CHAMP Assistance Dogs in St. Louis, Missouri, and has been in training since he was just a pup.

A little background: I was diagnosed with CMT at a young age. It affects mainly my legs and feet, making activities like climbing stairs, walking on uneven surfaces and getting up off the floor difficult. Growing up, I have been lucky to have great friends, teachers, and family willing to help me with these activities. However, as I got older and closer to college, I wanted to be more independent. After some research, my parents and I decided that a service dog would be a good fit.

I've only had Whitt for a short time, but I can already tell he will make a world of a difference for me. He wears a harness with a handle that I can hold onto to assist with my balance on uneven surfaces and stairs. He also can brace his body against mine, allowing me to push off of him to get up off the floor. He can even pick up items that I drop and carry things for a short distance.

Having Whitt by my side will give me more confidence to explore and expand my comfort zone. He may not cure my CMT, but he will eliminate some of the barriers it creates and allow me to participate more in life. I'm excited to go out with my friends and not have to worry about keeping up with them on uneven surfaces. I can't wait to cross a street and not worry about falling and not being able to get back up. I'm looking forward to conquering steps that don't have railings.

What I'm most excited about, though, is the companionship and partnership we will have. Whitt and I are going to have a special relationship. He will help take away some of the physical barriers created by CMT and I will give him my full love, care and companionship. I'm excited about our future adventures together and can't wait to experience life with him by my side.





Okay, Cupid

*By Bethany Meloche**

[Editor's note: This is an excerpt from the book "How Should a Body Be?"* by the CMTA's social media director, Bethany Meloche, who began volunteering for the CMTA as a teenager.]

When I was 17—after years of research and preparation—I started attending Juniata College in the snowy hills of Pennsylvania. I then turned my attention to an even more urgent matter. Namely, getting a boyfriend. My approach to romance was not so different than my approach to any other goal: getting into college, getting A's, understanding my disease.

It required diligent research and a step-by-step strategy.

Trying to date on campus was quickly eliminated as an option. Juniata was known for being a majority female college, with only 1600 students in the student body. So, with roughly 600 of them male, you can assume that at least half of those 600 are taken, and another half of those would not meet my qualifications, and another half of those who wouldn't consider me to meet their qualifications...

You get the picture. Pickings were slim. Add to that the fact that I didn't have the energy—or the feet—needed to socialize at parties. (At this point my feet hurt so badly when walking that I often skipped going to the cafeteria for dinner so that I would be able to make it to lab the next morning.) I also assumed—rightly or not—that the motorized wheelchair (although I preferred the term "scooter") I needed to traverse the campus might be an immediate turnoff.

I quickly settled on online dating.

I waited until my eighteenth birthday—you have to be eighteen to sign up; I would have started earlier if I could—and immediately began my research: identifying prospects, taking notes, drafting the perfect first messages.

There was one dilemma, which was how to approach my disease/disability/illness/injury/situation/what have you. I saw three options:

- A. Girl and boy meet for their first date. Surprise, wheelchair!
- B. Girl first charms boy with her incredible personality through several messages or phone calls, and then breaks the news.
- C. Girl says what's what on her profile.

Option A seemed bordering on deception, and both A or B offered the risk of to-my-face rejection.

And so I chose option C. Of course this meant many potential suitors could disqualify me immediately, but... so what? I had to make that be okay in order to survive this already rejection-centric process. I knew intellectually that it would be difficult to date someone with a disease/disability/illness/injury/

situation/what have you, and I also knew that people dismiss partners for much sillier reasons like bad taste in music or literature. It wasn't personal, I told myself. Just ... preferences! That said, I preferred to avoid direct face-to-face rejection, opting instead for a process that wouldn't let me know if I'd been cast aside or not.

I went for a carefully crafted two sentences in my profile—under the category **The Most Private Thing I'm Willing to Admit**: "I have a neuromuscular disease and use a scooter to get between buildings on campus. But it hasn't stopped me from living an awesome and full life."

And there was definitely a smiley face at the end. To show that I'm super cool with it.
:-)

On December 7, less than two weeks into my search, I logged on and a new match popped up on the front page.

Username: sinclair44 - **Match percentage:** 87% - **Enemy percentage:** 7%

Age: 20 - **Location:** Pittsburgh, PA - **Photo:** Wearing a top hat; cute

Click.

Sinclair44's profile was both unusually well-written and long, especially considering it said he had signed up for the site that day.

I sent him a message immediately. Four carefully chosen sentences, one emoticon.

When I woke up the next morning at 6:30 for my Invertebrate Zoology lab, the first thing I did was check my messages.

He had responded. Score.

His response was seven paragraphs long. And he had upped the emoticon game to four.

It ended with:

How long do these responses typically go on? If writing a 3000 character essay in response to a simple question is overly excessive, please excuse me since I haven't really done this very much at all. :)

Curious to hear from you!

Josh



"I'd love to hear more about type theory," I found myself saying—or rather, typing—to Josh after hours of messaging back and forth over a period of a few days.

This was not true. Although it was true that I was interested in hearing him talk—actually talk, hear his voice on the phone for the first time—even if it was about something as boring as type theory probably was.

And so we agreed to have a call—later—giving me enough time to first read the Wikipedia article on type theory so I could come prepared with an intelligent question. (It worked, by the way, prompting the response, "That's a really good question, and there is a lot of debate...")

That first call lasted only five minutes, which was good since I only had one question prepared. My parents got home just after Josh had explained the intricacies of the type theory debate; I didn't want to listen to my dad making fun of me, so I hung up before my parents could hear me say, "Oh, fascinating, wow, never thought of infinite recursion that way!"

I was home for winter break now, and just a few days prior—about a week after I sent Josh that first message—I had been in the process of sitting down on the toilet when I felt my kneecap pop out and back into place. (Why is it never something dignified?)

And so for the second time my bed was brought down to the dining room where I would spend the entirety of my days while my knee healed. Having my potential suitor to talk to online made the fact that I couldn't walk easier to handle, although it would have been nice to have a little more privacy.

One night, not long after my introduction to type theory, Josh and I were up late messaging each other and our parents had long since gone to bed.

This was the opportunity to have a real conversation on the phone.

We stayed up all night talking—about ourselves and our

Continued -

answers to the weird dating site questions and how much funnier fortune cookie fortunes are if you add “...while I watch” to the end of them.

We talked until 6:30 in the morning. And all night again the next day. And the next.

We were both clearly enamored by each other, and I didn’t want our calls or our conversations to end. But my happiness was short-lived, as it was after one of these long calls that he sent the message I’d been dreading:

“There’s something I’ve been meaning to ask you.”

But—he said—he was too tired now; it would have to wait until tomorrow.

I knew what he wanted to ask me. I’d been waiting for it the entire time. Honestly, I was surprised it hadn’t come sooner. Extra honestly, it had been really fun to not even have to address it.

He was finally going to ask me about my disease/disability/illness/injury/situation/what have you. He was going to ask, essentially, “So, how disabled are you?”

I went to bed that night dreading The Question. I went through the imaginary conversation in my head twenty different times and twenty different ways. Had I just been kidding myself that this was something a twenty-year-old could look past?

My plan to minimize rejection was not looking so great.

THE FOLLOWING EVENING

Josh has signed on.

Bethany: So what was it you wanted to ask me?

Josh: Oh, yeah...

Josh is typing...

[three painful minutes elapse]

Finally he hit “send” on the novel he had apparently been composing. The Question had finally come, in the form of a very long, obviously nervous, and semi-rambling paragraph. The only part that mattered to me was this:

“Would you like to go on a date with me?”

We set our first date for January 23, 2010, when we would both be back in school from winter break, and my knee would be all healed up. Otherwise our first date would have had to be in my kitchen, which didn’t seem a thousand percent ideal for budding romance. The plan was that Josh would take the three-hour train ride from his college, Carnegie Mellon, in Pittsburgh, to Juniata College in Huntingdon, Pennsylvania, and we would... see what happened.

He set a countdown on his computer and we started counting down the days.

The morning of our date I tried to distract myself with articles and games on the computer—even homework—to avoid worrying about the impending visit. But it was impossible to forget, especially as Josh sent periodic updates (“T minus 4 hours!” “At the train station!”) and our countdown changed from hours to minutes. I changed shirts three times, settling on one with the pi symbol (sure to woo a computer science/physics double major). I paced around the room—mentally. I brushed my hair, which didn’t need brushing.

Josh: ETA 5 minutes!

Josh: I’m wearing a green jacket.

Sure enough, a couple minutes later I saw a guy wearing a green jacket walking up the hill toward my dorm. I watched him, waiting for him to see me, shifting my weight back and forth nervously. I saw him look in my direction—surely he had seen me—I was standing outside the front door—but then he looked away and kept walking. Past me and my building.

My heart dropped. Had he really taken one look at me and suddenly changed his mind? Was I standing funny? Or just that ugly?

These were the horrible thoughts running through my head when I saw a second guy coming up the hill toward me.

He was wearing a green jacket.

It was him.

*You can buy “How Should a Body Be?” at amazon.com.

Bethany is now married to “him” and lives in London.



Searching for Your Sport

*By Emerald Fox**

My grandmother and I explained my CMT to the coach and his answer was, “Well that’s great, but you’re sliding your foot, not running down the lane.”



Hello, my name is Emerald Fox. I am 17 and I have CMT. Even though can’t participate in a wide variety of sports, I have two things I love—riding horses and bowling. I have learned people can’t tell me I can’t do a sport when I know that I can. I wish that I had showed the coaches and other students in junior high that my CMT doesn’t make me different. Yes, I know I’ll hurt afterwards, but it’s worth it to me.

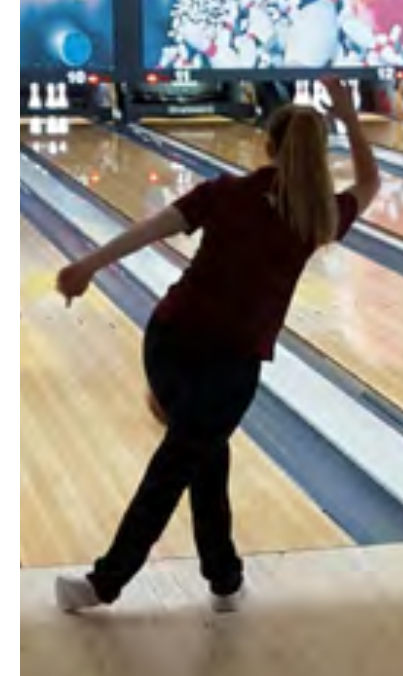
Let’s start at the beginning. My mother has CMT, but she never suspected that I had it because: 1) my other siblings didn’t have it and 2) she wasn’t always there to notice. I have gone through a lot—maybe not like others, but it was hard. With both parents out of the picture, I was in a tough situation. I had my sister, who was always there for me. She clothed me, fed me, and sat with me when I was in pain.

I moved in with my grandmother at the age of 5. My grandma kept telling doctors something wasn’t right, but they wouldn’t listen. My grandma put my sister and me into gymnastics, but I couldn’t even get past the beginners’ stage because the stretching hurt too much. I sure couldn’t balance on the balance beam. So we just thought gymnastics wasn’t for me. Because I was a tomboy, we thought maybe karate would work, but sadly that also hurt. The stretches were terrible and highly painful. We didn’t know what was going on, so we went to the doctors and they asked about our family history. They suggested we go to a specialist, so we did. At the age 6, I was diagnosed with CMT.

Having a diagnosis made it easier to handle the situation, but it was still depressing considering I couldn’t do what other kids my age could. When I got into junior high, I wanted to try cheerleading, but I couldn’t do flips. I thought volleyball might work because it doesn’t take that much to hit a ball over a net, but it took more than I had. All I wanted to do was be active. The only sport I did was bowl and that was outside of school. My sister and I were in a league and so were my grandparents.

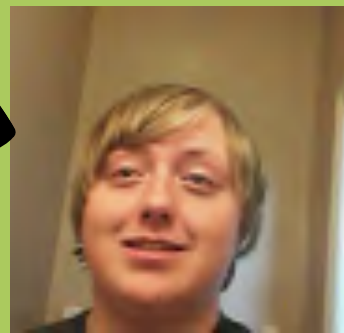
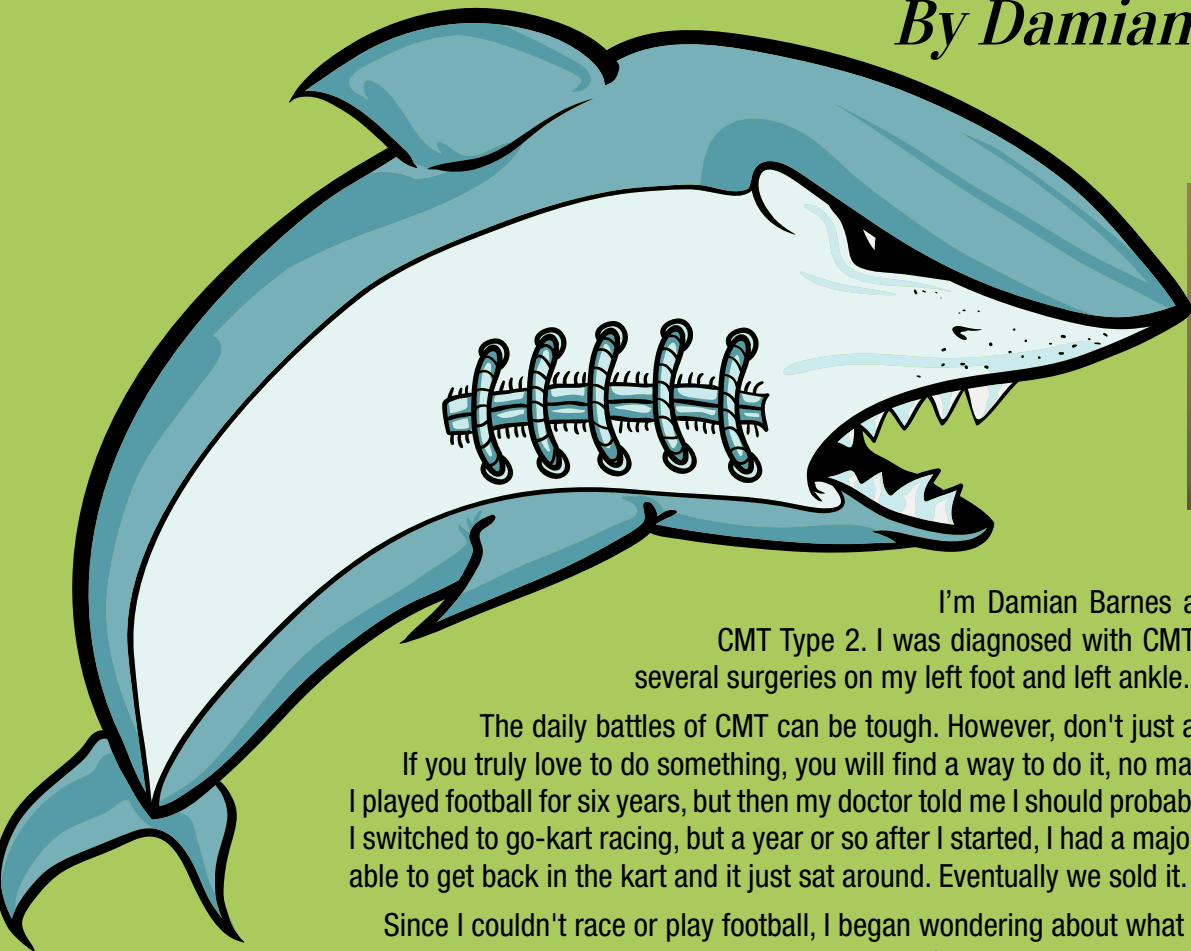
Going into high school, I didn’t know what to do to be active. I finally found out there was a bowling team at school. My grandmother and I explained my CMT to the coach and his answer was, “Well that’s great, but you’re sliding your foot, not running down the lane.” I was waiting for him to say no, but I tried out for the team, and to my surprise I got in. I am now a junior and next year will be my last year bowling for that team, which is very sad. But that’s okay because I won’t stop bowling. I’ll be going to a college that has a bowling team and I’ll bowl for them too, if I get in.

Bowling is one of my favorite things to do, but it isn’t the only thing. I also ride horses. Bowling is great, but it doesn’t really keep me calm. I mean when you try getting a strike and it doesn’t happen, you get upset. A lot of love goes into riding a horse. Before you saddle a horse you have to brush it to get rid of anything that might make it uncomfortable. But it also helps the horse get used to you and your emotions. You brush the horse so you calm down and the horse understands you that day and doesn’t decide it wants to buck you off.



The Battle of CMT

By *Damian Barnes**



I'm Damian Barnes and I'm 17 years old. I have CMT Type 2. I was diagnosed with CMT around 2012 and have had several surgeries on my left foot and left ankle.

The daily battles of CMT can be tough. However, don't just assume nothing can be done. If you truly love to do something, you will find a way to do it, no matter what stands in your way. I played football for six years, but then my doctor told me I should probably not be in contact sports. So I switched to go-kart racing, but a year or so after I started, I had a major surgery on my foot. I wasn't able to get back in the kart and it just sat around. Eventually we sold it.

Since I couldn't race or play football, I began wondering about what I could do with myself. A kid in my neighborhood—Braydon, a great kid and a fast learner—asked me if I could help him train for football and baseball. I saw this as an opportunity to become involved again. For the last two years, I've worked with him every time he wanted to train for football or baseball. I taught the kid everything I know about both sports. This was my way of getting back in touch with the things I loved to do. So even though I can't play football, I can teach kids who are interested in learning how to play and also teach them some life lessons along the way.

Even if I didn't run, I was still worn out from training Braydon by the time I got home, and my legs were aching, but I didn't want to give up practicing with the kids. I kept adding padding or whatever I needed to make my leg brace as comfortable as it could be. Eventually I got the adjustment just right and was able to continue to do what I wanted to. So even though there may be some pain and tears along the way, you can find ways around this disease. It can be tough. It will make a person want to give up; however, if we give up we let the disease win. We have to fight. We have to find ways to make ourselves comfortable. We have to take a stand and we have to say we can instead of saying we can't.

Keep strong, keep fighting, and keep positive. Don't let this disease get you down because it's tough. Keep positive because you have passed all of the disease's test at this point in life.

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