

# FACES OF CMT

RARE DISEASE DAY 2021

Photography Competition



**CMTA**  
Charcot-Marie-Tooth Association  
TREATMENT-DRIVEN • COMMUNITY-POWERED



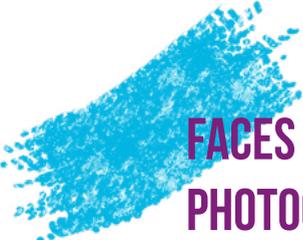
HEREDITARY  
NEUROPATHY  
FOUNDATION

EUROPEAN  
**CMT**  
FEDERATION

With support from:







# FACES OF CMT PHOTOGRAPHY COMPETITION

To mark Rare Disease Day 2021, the inaugural “Faces of CMT Photography Competition” was launched by The European Charcot-Marie-Tooth Federation (ECMTF), The Hereditary Neuropathy Foundation (HNF) and The Charcot-Marie-Tooth USA Association (CMTA), supported by Pharnext, to raise awareness of the challenges of living with CMT and the strategies used by individuals to overcome them.

The competition was open to everyone around the world, for those with CMT or those living alongside someone with CMT. We were delighted by the level of response from all areas of the world and were inspired by the submissions and stories we’ve read. We want to thank you all for your participation and helping us spread awareness of this disease. To celebrate everyone’s participation, we’ve published all of the creative, impactful and heartfelt submissions in our digital book.

Many congratulations to Sandra Fernández Vega, Michela Padovan and Laura Llorens in the over 16 years category, and Brook Phipps, Seamus O’Neill & Ashlyn Montisanti in the under 16 years category on coming first, second and third and from all of us at ECMTF, HNF, CMTA and Pharnext, thank you to all who participated and helped with the event.

Do please continue to help us raise awareness of CMT, no matter where you are in the world, as we strive to bring suitable treatments for all those affected with this disease.



## What is Rare Disease Day?

Rare Disease Day takes place every year on the last day of February and unites the world under a single theme to highlight rare diseases worldwide. There are over 300 million people living with a rare disease around the world, and they and their families face common challenges in their daily lives. As a vulnerable population, they are unfortunately heavily affected by stigma and social marginalisation in society at large. Rare Disease Day provides an opportunity to call for awareness not only of rare diseases, but also of the societal issues associated and to increase equity for those living with rare diseases in addition to their families. There are over 6,000 rare diseases worldwide, which are progressive, degenerative and often life threatening, however information and expertise can be limited for each individual disease. Rare Disease Day aims to bring awareness to the lack of coverage by health systems worldwide and call on governments to extend coverage to people living with a rare disease, reduce the diagnosis time, improve and expand services and prevent further financial hardship by reducing out-of-pocket expenses.

## Charcot-Marie-Tooth Disease and Charcot-Marie-Tooth Disease Type 1A

Charcot-Marie-Tooth disease is a condition that causes deterioration of the peripheral nerves controlling sensory information and muscle function in the feet, lower legs, hands and forearms. It is caused by mutations in specific genes that affect the transmission of signals up and down the nerves in the body outside of the

spinal cord and is the most common inherited neurological condition. There are many different forms of CMT, with each type corresponding to a specific gene mutation, however the two most common are demyelinating forms and axonal forms which damage the nerves themselves. Demyelinating forms reduce the myelin sheath which impairs conduction of signals down a nerve, resulting in reduced muscle function and muscle atrophy, while axonal forms damage the nerves themselves which results in muscular weakness, atrophy, and a loss of sensation. Some common symptoms include weakness in feet, ankles and legs, fingers, and hands, reduced gripping strength, overall fatigue, joint and nerve pain, and difficulty in completing fine motor tasks, such as using buttons.

Charcot-Marie-Tooth disease type 1A (CMT1A) is the most frequent form of CMT and is a slowly progressive, autosomal dominant, demyelinating peripheral neuropathy affecting almost 1 in 5,000 people worldwide [1-3]. Despite the understanding of the types of CMT, there are no current curative or disease-modifying therapies available. Current treatment consists of supportive care, such as orthotics, leg braces, physical and occupational therapy or surgery which aim to help patients reduce pain and improve or restore mobility.

Through the Faces of CMT Photography Competition we aim to raise awareness of an often-overlooked disease which affects millions of people worldwide with the hope of improving treatments in the future and access to services that could greatly help those with CMT.

## The European Charcot-Marie-Tooth Federation (ECMTF)

The ECMTF is a non-profit organization founded in 2018, formed by 15 European national associations supporting people affected by Charcot-Marie-Tooth, representing the CMT PAGs reference point in Europe, and grouping more than 1/3 of people suffering from CMT in Europe.

The Federation's primary goals are to encourage research projects for an affordable and effective treatment for CMT, to promote communication and collaboration between CMT organizations/charities, to provide help and advice for the creation of further CMT organizations where no such organization exists currently, and, last but not least, to raise awareness on CMT.

To face the lack of knowledge of CMT that accompanies the lack of diagnosis, the Federation actively organizes campaigns to inform and raise awareness on this rare disease. The next campaign, the fifth one, will take place next October.

The Federation strongly believes in the power of cooperation between the CMT organizations and institutional or scientific stakeholders. The union of skills and experiences is the main engine to guarantee the interests of the CMT community.

The Federation's motto is "Together we are stronger."

## The Hereditary Neuropathy Foundation (HNF)

HNF is a non-profit 501(c)3 advocacy and

research organization with a mission to increase awareness and accurate diagnosis of CMT, and related inherited neuropathies, support patients and families with critical information to improve quality of life, and fund research that will lead to treatments and cures.

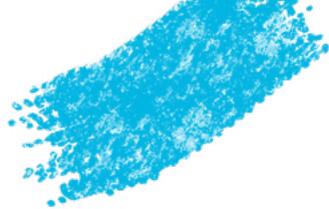
HNF developed the Therapeutic Research in Accelerated Discovery (TRIAD) as

a collaborative effort with academia, government, and industry to develop treatments for CMT. Currently, TRIAD involves many groups that span the drug discovery, drug development, and diagnostics continuum. HNF is actively committed to increasing awareness and accurate diagnosis of CMT and related inherited neuropathies.

Major projects include the production of a critically acclaimed documentary, a children's book series, a monumental meeting with the FDA and the development of research tools (animal and cellular models) and dozens of research collaborations and industry partnerships, as well as establishing CMT Centers of Excellence, identifying clinical sites for drug trials and providing seed funding for startup biotech companies and other potential projects to support the development of therapies.

### **HNF is patient powered, patient centered and patient driven!**

HNFs online Inspire® Support Community, the patient registry, Global Registry for Inherited Neuropathies (GRIN), and the Movement is Medicine™ Program is the core that continues to support HNFs mission.



## The Charcot-Marie-Tooth Association (CMTA)

Founded in 1983, the CMTA is a non-profit organization dedicated to driving the development of new drugs to treat CMT, meeting the daily needs of patients with CMT, and accelerating research for a cure.

The largest charitable funder of CMT research, the CMTA has invested more than \$17M since launching its Strategy to Accelerate Research program (STAR) in 2008. With over 50 active research projects and more than 30 pharmaceutical and industry partners, STAR brings together best-in-class researchers, biotech companies, and patients to find treatments for CMT.

The CMTA was founded by a patient, and to this day is powered by a community of patients who are all rallying behind its mission. With the largest constituency of CMT families around the world, the CMTA actively works with the patient community in the drug development process to ensure patients are partners every step of the way.

### References

- [1] Bird T.D. Charcot-Marie-Tooth Neuropathy Type 1, in GeneReviews®, Pagon R.A. et al. Editors, Seattle (WA), last revision: March 26, 2015.
- [2] McCorquodale D., Pucillo E.M. and Johnson N.E. J Multidiscip Healthc 2016;9:7-19.
- [3] Shy M.E. et al. Neurology 2008; 70(5): 378-83.





WINNERS

FACES OF CMT

**WINNERS  
& FINALISTS**





## FIRST PRIZE - OVER 16

### Sandra Fernández Vega

My scars are my constellations.

With each surgical scar due to Charcot Marie Tooth disease, I have learned to value each moment. They are my personal set of stars and they are part of the times that have changed my life and my body forever. Behind them there are moments that I would not change for anything else. The most important thing of those moments was my strength: what they gave me and the strength I drew from deep inside to go ahead.

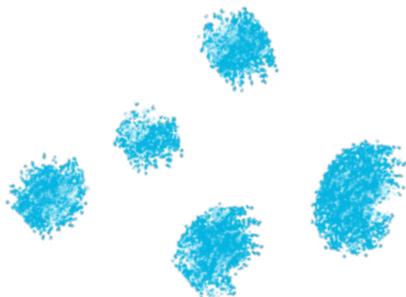
Since childhood, I was taught to never give up, to always fly high.



## SECOND PRIZE - OVER 16

### Michela Padovan

I have CMT disease and move myself by a wheelchair. The picture was taken when I was at the last year in the High School with my classmate Riccardo. During my school-life Riccardo helped me to overcome any obstacle so when we have to do the picture for the yearbook, it seemed more beautiful to take the photo together to celebrate our friendship. It encloses any time I felt in difficulty, any moment I felt sad or embarrassed but also that anything is not so big when you have a friend that “elevates” you.





## THIRD PRIZE - OVER 16

### Laura Llorens

#### Daily struggle

We are three generations affected by Charcot-Marie-Tooth. Every day we fight to live normally.

Different symptoms, pains and weaknesses but the same fight.

Rare disease, progressive and gene unknown.

We fight every day to make ourselves understood.

We don't see it, we don't listen to us, we don't hear us.

Disease partially invisible but present.

We know our abilities, but we find it hard to be heard when we say we are capable. But also to make us listen when we talk about our difficulties.

But together, hand in hand, we manage to get through the difficult times.



## FIRST PRIZE - UNDER 16

### Brook Phipps

As a mother, I am helping my 15 year old daughter face challenges of CMT: bullying from peers, having favorite activities like gymnastics taken away by physicians, frequent physical/emotional pain, and the self awareness that her feet do not appear normal to others. Her physician at Shrinners allowed her to continue with dance in order to build her depleting emotional confidence. This has resulted in the enhancement of Brook's inner beauty. A mirror only reflects the outward beauty. CMT has made Brook focus on peace, serenity, confidence, kindness and generosity- inner beauty that will last her a lifetime.



## SECOND PRIZE - UNDER 16

### Seamus O'Neill

Seamus is our hero. Diagnosed two years ago, Seamus never lets his CMT stop him from trying. In July 2019, two weeks after bilateral foot surgery, he had the opportunity to take batting practice at Fenway. In pain and unable to walk, he was not going to let this opportunity get away. His positive attitude helped him that day and helps him live with CMT every day. Adapting to overcome any obstacle he faces is how he moves forward. When he can't run, he walks. When he can't walk, he wheels. And he does it all with a smile.





### THIRD PRIZE - UNDER 16

**Ashlyn Montisanti**

#### **Stuck**

My feet are stuck in the snow to demonstrate the feeling of walking with CMT. Continuously, I sense that I cannot raise my feet off the ground, almost as if I'm trying to elevate the heavy snow pressured against my feet. Other times, I sense nothing, similar to when snow freezes my feet causing them to feel numb. Daily stretching is very beneficial to me, and it helps me encounter this obstacle less. It strengthens my muscles so that I experience less falling and loss of sense and balance. For that reason, I motivate myself to exercise every day!

# RUNNERS-

**THE GLOBAL FACES OF CMT**

# RUNNERS-UP

# UP



## Katuscia Tarabella

My name is Katuscia and I suffer from CMT1A. It has caused me so many problems but I don't want to surrender.

In this picture, I'm showing how, among many difficulties, I have relearned how to hold a pencil in my hand, in order to write and, above all, to draw, which is my passion. CMT is really making me struggle but I will never give up. She had made me lose my ability to write but I started all over again like kids do when they go to school and learn to write for the first time.

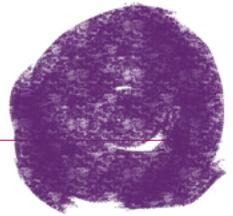


## Anett Etesy

Anett is now 13 years old. Slowly 7 years ago, our Calvary began. Every day, Anett is about to show, prove to yourself, to everyone, that you **MUST NOT GIVE UP!** I'll be honest: many times she gives me and my partner the strength to continue on this path we've been given. He always smiles. Smile! Whatever happens, she does it with a smile. Anett goes to normal school, wants to be a sign language interpreter and also loves the guitar. This awfully great power, faith, love that is in it makes me stronger. In a word, I **LOVE**. I don't know what the future holds, I don't know what awaits us yet, I don't know what my daughter's illness hides for us, but I know one thing for sure: **NEVER GIVE UP!**

## Sara Carreras

Growing up, my CMT symptoms were very manageable - a bit of weakness in my extremities, poor balance, and avoiding hikes at all costs. After I was diagnosed with Leukemia last year, however, all of that changed. As a result of intense chemotherapy, radiation, and a Bone Marrow Transplant, my neuropathy worsened very rapidly. I have been very grateful to have my dog April with me during this process, who helps me stay active. Playing fetch with her and going on walks together has helped me regain my mobility and motivated me to keep moving forward.



## Anny Mariniello

I'm Annarita Mariniello, aged 25 and I am affected by CMT 2 category Z. My hobby is Caribbean dance.

At a Caribbean evening the various styles of this genre alternate, I concentrated my strength on bachata sensual and group dances. Obviously, to avoid getting exhausted between one dance and another, I stop to recharge my batteries.

Fundamentals for me are:

1- the choice of the partner, who must know how to guide me so as not to make me lose my balance.

2- the talcum powder, with which I sprinkle the soles of my shoes in order to glide better. The stepping gait helps me to be more sensual.

## Anna Francesca Dodaro

I am Anna Francesca Dodaro and I am 38 years old. I am a rare mother, rare just like my illness which, despite the difficulties, has allowed me to lose myself in the gaze of my two jewels. I am a person with a fluctuating mood but happy because God chose me to test me if I was able to endure so many difficulties .... well moments of tears and despair are not lacking but I am stronger and the CMT is an acronym walking by my side together with my guardian angel Angelo.



## Deborah Cice

Hi, I'm Deborah Cice, I am 42 years old and I pedal every day to keep my legs active.



## Larisa Sheloukhova

One of the toughest challenges CMT made me face was the realization I could not dance anymore. My symptoms started when I was an active teenage member of a dance troupe in Russia. The inability to lift my heels off the floor which seemed to have appeared out of the blue made me abandon dancing and embark on a merry-go-round of doctors. 15 years later I decided to try pole dance. At first, my feet and hands would not cooperate. Now I do short pole combinations and inspire Russian-speaking CMTers to work out as much as they can.



## Jerome Mossay

Our identity is evolving, our support is degrading. Isolated, let's fight in our entity to the dice / en-faces



## Ed Linde

Adaptation – a word I have become very familiar with. As I grow older and my CMT progresses, I have realized that if I want to continue the life I enjoy I must be able to adapt to my ever-changing condition. Being in a wheelchair and depending on others, I could very easily be in a constant state of depression. However, I view each day as a new challenge. What do I want and how can I do it? I believe you have to keep moving forward and not let the challenges in life, including those of CMT, stop you from your passion.



## El Mrani Roba





## Kathryn Williams

One of my earliest recollections was of my Mother and Grandmother discussing how much my feet looked like my Grandfather's. This is a picture of us on my last visit with him. He was barefoot because he spent most of the day in bed, I had never actually seen his feet before. You can't tell the size difference in this picture but he wore a men's size 10 and I wore a women's size 5. My feet looked like a miniature version of his, the shape is identical. You can also see the difference in progression in our hands.

## Cierra Kephart

I get up every morning with a healthy mindset, some days it's a struggle, but I remind myself that I'm a million times better than this disease and I won't let it take over. I have a lot of challenges throughout the day, getting a shower, brushing my teeth, also putting my makeup on since I don't have the use of my fingers or legs. I've learned to adapt to a bunch of stuff during my journey with CMT. CMT has taught me so much about living life through the eyes of a physically disabled person. If I ever catch myself saying "I can't do this", I reply with "there's no such thing as can't, you can". That's what gets me through it.



## Abigail Garde-Upton



Here is a picture of me doing a zip line upside down in Puerto Rico. At first I didn't think I would be able to do it because I have bad balance and muscle weakness, I thought I'd struggle getting in and out and NO WAY could I go upside down. However, with the support and assistance of those around me, they were able to lift me into position and it was AMAZING. Nothing is impossible with CMT, it's just about using support finding another way!

## Marie-Hélène Gerard

### Baptism in a hot air balloon

Living with CMT means surpassing yourself at every moment, going beyond your strength to move forward every day. But it is also knowing how to take advantage of exceptional moments of freedom during a hot-air balloon flight, thanks to people who make it accessible to all. These moments are extraordinary, and the disease disappears into thin air.



## Mary Ward

Living with CMT in sunny Florida, I struggle wearing my AFOs in public. I love the beach but hate that I can't wear normal sandals, so I rarely go. When my sister visited, she wanted to go to the beach right away. I secretly cried knowing I'd have to be in public. However, I'm so thankful I did. I found cool seashells and best of all, spent some much-needed quality time with my sister soaking up the sounds of the ocean. Never give up what you enjoy, even if you are scared.



## Riese Goerlich

This photo was taken the same year I was officially diagnosed with CMT. I was only 17 at the time and grappling with the sudden changes in my body as I balanced school, physical therapy, and extracurricular activities. The photo represents my determination to keep moving forward, from hiking mountains to continuing my bachelor's degree in engineering.



## Brigitte Below

It's good for me to walk a lot of small paths, that brings me to about 6,800 steps a day. I think that's good for my level of illness. Outside of my apartment, I use forearm crutches, but I can't walk more than 10 minutes at a time at my slow pace. I use a wheelchair for longer trips. It happens again and again that I can't anymore, and have to use the wheelchair in the apartment. My basic attitude is: to use the tools as early as possible so that I can largely do what I want.



## Alessandra Donati

My name is Alessandra Donati, I'm Italian and I have CMT1A. This doesn't stop me from playing golf, my greatest passion. I would like to tell everyone that we must never give up and have fun! I am an EDGA Advocate (European Disabled Golf Association [www.edgagolf.com](http://www.edgagolf.com)) and I introduce disabled people of all kinds to golf. In this picture I'm playing golf, with my golf quad.

## Seba Magued

If it seems hard to push through a challenge, consider renaming it. My faith tells me I've given what I can handle. So the treat; thought it might taste bitter; was a sign, vibration in my gut saying "you can handle this". Whatever this was, I could handle it for I chose to. I speak of my journey as enabling me to rewire beliefs around challenges.

The treats where an affirmation I was choosing wisely, reinforcing I was capable beyond measure. My gut flourishes with every treat, an increasing vibration.

I am me and CMT is one of my treats.



## Keili Hastings

This is my daughter, Keili. She is the first known case of CMT in our family, diagnosed at age 15. Now at 19, she struggles to find employment that will accommodate her restrictions. She can't stand for long periods, lift large amounts of weight, or work several shifts in a row. Her puppy, Luna, is searching for a trainer near their home to help her in becoming a professional assistant for her human! Luckily, Keili's fiance is in the army, so hopefully they don't have too much trouble finding a trainer. We know that the struggles Keili faces will only get harder over time, but she refuses to let CMT take her down. She has had surgery to attempt to correct hip dysplasia on one side (both sides are deformed) but it was only partially helpful. I wish I could take the pain and frustration from her. I would take it all on myself to save her, and my younger kids, from ever suffering.



## Tamela Bell

“Enjoy everything”, that is my motto. I get up every morning, thank God for being able to get up and get dressed on my own. I drive to work every day and I lead my department to get the job done. I am the first disabled, Afro-American woman to make manager for my company. I go to meetings, go to church and with the help of my coworkers, children and husband I can do all things that life has to throw at me. CMT is not a curse, it can be a blessing, you can show others that you are strong and you can do anything. I am also a positive example for my family members who have CMT, we have nurses and lawyers who have overcome their disability and succeeded and that makes me proud and blessed!



## Andres Coronado

Andres Coronado is 10 years old. He has CMT1A, also Autism with other disabilities. I raised my grandson Andres. He's a pretty happy boy. We live in Kenosha, Wisconsin. He loves swimming, bowling, gaming, carnivals and science projects.

## Charlie Cook

Living with CMT is like having to constantly pretend you're ok, when really you just want to scream to the world that you aren't. I've learnt if you truly want to be at peace with yourself, you have to be your own best friend, don't waste time fearing judgement and learn the people who judge aren't living your life.



## Nick Addy

Hi, I've sent a picture of me in my CMT cycling kit I designed using the CMT logo, hopefully to increase awareness.





## Todd Sewell

CMT currently affects 6 members of my family across 3 different generations. Luckily, my brother & I have been fortunate enough to have surgery at a young age to help try and correct some of the effects of CMT, however my mother, uncle & grandad have not been so lucky. To try and inspire others to show that CMT does not need to limit your life, my brother is currently completing a challenge to run 100 miles in February, which is a challenge that we never thought possible when we were diagnosed. He has currently raised upwards of £1,800 for CMT UK. This photo shows his perseverance through all conditions to complete the challenge!

## Henriette Smith

### CMT-warrior

The epithet of my life: "I'm so Tiiiiired..". Always one step or 50 behind everyone else in school. Never able to keep up.

It made me resilient.

Independent. Strong in mind, if not in body. And a bit reckless.

Climbing the main mast of a tallship even if it technically was too hard. Travelling the world to study and sail in every corner of the world.

I realised that maybe I could perform not in spite of, but with my challenge. In adapted boat and adapted braces, I now compete in the sport of my heart, on my terms.



## Emma Chester

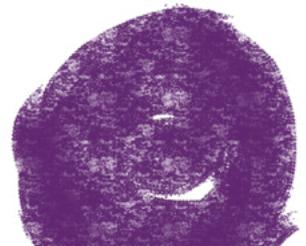
My biggest challenge with CMT is finding appropriate footwear. Being young and female my friends have wardrobe full of shoes, I envy them.

I've learnt that when I find a shoe that fits I buy multiple pairs! Dr. Martens have a soft leather shoe that's great for work. My biggest success was accessorising flip flops for my wedding with beautiful clip on broaches. Very comfortable and went perfect with my boho theme! Photo of me and my late grandad - both of us had CMT.



## Rosie Hager & Denise Snow

Rosie Hager and Denise Snow zoom along the Seattle waterfront.





## Mike Short

My name is Mike and I love my bike.  
The challenge is to ride it, stay  
upright and strong,  
As I glide along those bridle paths  
all day long.  
It's not easy these days with CMT,  
But sod it if I'm not going to be  
beaten that easily.  
I wear AFOs you see, I wear them  
from just below the knee.  
And yes at times they hurt my  
legs, feet and toes,  
The pain I've suffered only God  
truly knows.  
But there is immense enjoyment  
for me,  
In knowing I can still get out every  
day and get back for me tea!

## Liane Schlickerieder

A piece of shoe string turns  
that damned zipper into  
my best friend. If only it  
were this simple all the  
time!





## Nicoleta Poganu

I am a member of Association Charcot Marie Tooth Romania, the target group representative of it. I am the face of CMT too and I love this photography competition I'd like to congratulate you for. "The challenges living with CMT and the strategies to overcome it" are all about love and work. I live for love and I'd be nothing without it but my sense is also the work.



## Kristýna Šedivá

One of the challenges about living with CMT for me is having to only wear fixed shoes (even in the summer). Like every girl, I always wanted to dress pretty, but not every dress or skirt looks good with sneakers and at some events it is not appropriate to wear sneakers. But time and fashion are changing and sneakers are more accepted in business and formal fashion, which is great, because I work in an economic profession. So I say, let's keep sneakers trendy! I know that this is not some serious problem, but it does affect and sometimes frustrates me.

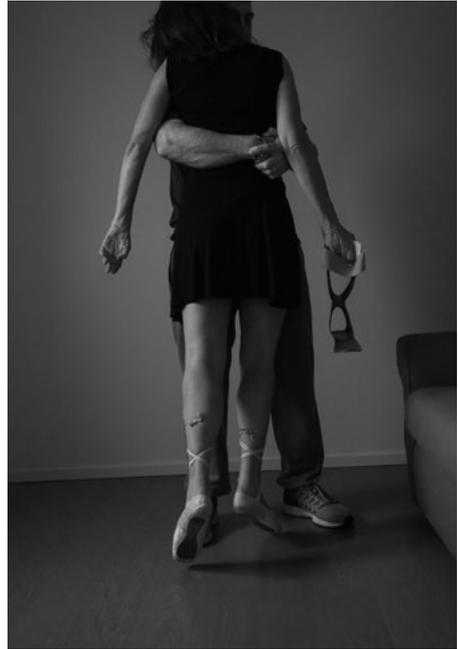


## Rita Ricco

Speaking about the CMT, we must first talk about lack of looks. For me there was no “before” and “after”, but a slow and progressive worsening of physical skills, often not immediately perceptible to the eyes of the world.

But the disease has been there, consuming the nerves, deforming and weakening my limbs, demanding attention in order to continue to exist; removing these “imperfections” from our gaze means we don’t want to reveal ourselves to them. It’s a fight between a (sometimes) hated body, that manifests its surrender, and the mind which, instead, tries to elaborate the disease by clinging to life and asking for help... yes, for dancing too.

IF YOU HELP ME, I WILL DANCE TOO!



## Claudia Dagostino

This is my dad and I, both with CMT. We accepted it. The only advice I feel like giving is: the first rule is don't get discouraged, smile and face life day by day.





## Stefanie Sedlatzek

This photo of the gym shoes symbolise the wish of a person with CMT to move in a normal way, to do sports. But it's too difficult because you could go over on your ankle (see overturned shoe) and the legs and feet feel like lead, so you can't move forward the way you want to (see knotted shoelaces).

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## Leanne Cottrell

### A 50/50 choice

Married for less than a year when...  
'Babies next!'  
Not knowing the internal fight. The decision to be made as a CMTX carrier.

Children. No Children.  
CMT. No CMT.  
Boy = CMT. Girl = carrier.

Watching my family. The pain. Could we face that challenge?  
And then there we were. Watching a sonographer's screen.  
'It's a boy.'  
Silence. Shock. Love.

Will you take after me? We don't know, but we know you're perfect. The greatest decision.

They start again. 'You'll have another soon.' 'Wouldn't he love a sibling?'

"And don't you know that it's just you. Hey Jude, you'll do."



## Finn Neale

This amazing, strong 9 year old had his first procedure last summer. Stretching of his achilles, in cast for 6 weeks during the hot summer. Couldn't join in in the paddling pool with his siblings, but smiled throughout. Not one complaint. His aspirations are to become a vet, and he has the determination to do it. He is now awaiting his first surgical procedure and is looking like he will be in cast for his 10th birthday in April. Love him, admire him and wish I had his positivity and inner strength. My little hero!



## David Evans

My CMT was not diagnosed until my late 20's, but it impacted me before then.

As a child I could never ride a bicycle, my balance was never good enough. This photo was taken in the summer of 2019 and is of me and a volunteer, Carmen, cycling on a tandem in the Forest of Dean. It was the first time in over fifty years I had ridden a bike outside; it has not been my last – at the age of 58 I have brought the very first bike of my own, an accessible Trike.

## Claudia Besana



I have CMT4A, I move in a wheelchair and my hands are weak, but my character is strong and I love life. Since I was little, I have had the first symptoms and I learned to fight to reach my goals ... and until now I have always succeeded. Never give up. The important thing is the result, not how it is achieved, everyone has their means and I have mine.

## Christy DeLozier

Physical Challenges can be emotionally draining and quite isolating. I've met four amazingly strong, resilient women who share my same disease! We met at HNF's Movement Is Medicine summit in Nov 2019. We keep in touch and have found true connection during the pandemic. We maintain weekly zoom meetings; sharing movies, workouts, laughs, cries, passions, heartaches and frustrations. They have been my lifeline this past year and I'm grateful for these friendships. I encourage connection within the CMT community!! Summarized accurately: If you want to go fast, go alone. If you want to go far, go together - African Proverb



## Douglas Bayliss

### “Tip-Toeing Through the Grass”

This composite photo represents, for me, one of the many challenges I face living with CMT. I cannot walk up a hill to enjoy the shade with a friend, let alone walk on “tippy-toes” through the grass. Yet I take solace in nature. The smell of fresh cut grass, the scent from the tall pine trees and the warm sunlight, all pictured here, remind me of how extraordinary I am. Even the cat seems to look towards me with compassionate understanding. CMT is also a natural occurrence and while at times challenging, I take harbor in nature’s tranquility.



## Peter Neville

CMT has no boundaries or limits but together we stand strong, supporting each other and adapting our ways in life. Do what you can before you can't and always remember....  
There is no DISS in ABILITY!

## Massimo Peretti

My name is Massimo and my wife has CMT. One day she told me: "One day you wake up and you realise, you have the clear awareness that this disease, Charcot-Marie-Tooth, will never leave you... and it can only get worse!"

But little by little, we found out that we just have to live with it, sometimes struggling, sometimes giving up, sometimes looking for a workaround to lead a normal life!

Thus, as shown in this picture, the solution for keeping hiking we found was "The assisted walk", actually me pulling her with a rope!



## Rita Hillen

To stay active I started painting.

With this painting I show the life of our deceased sister.

With her Belgian husband, she ran a goat farm in the south of France, 50 km from Montpellier.

Goats were born and sold in the early spring. The late-born kids were lovingly cared for by my sister.

In the painting you can see her talking to the animals.



## Giuliana Ghizzi

### In the light.

The day that starts with a smile. Positive answers to every question. Work faced dutifully. Everyday life made up of proven certainties.

The evening comes with the abandonment of a day spent with the “faithful life partner”.

### In the shade.

The fatigue of another smile. The thoughtful answer to reassure oneself and others. The fatigue that work causes. Everyday life made up of apparent certainties. The evening, with its shadows projected on the future. But the shadows remain such and are flooded with light, become awareness and remain just a “projection”. We, with our body, are Light.



## Brody Baker

My name is Brody, I'm 10 years old and I have CMTX4. I live on a farm and help take care of my 4-H chickens. I play sports, too, but sometimes my feet and legs get tired and I fall sometimes during P.E. I wear braces at night, but otherwise life is pretty normal for me.



## Chris Wodke

"I run because I can, When I get tired I remember those who can't run, what they would do for this simple gift I take for granted and I run harder for them, I know they would do the same for me."  
-unknown.

I have dedicated my life as an athlete to raising awareness of CMT. I compete for the thousands of Americans with CMT that struggle to do even simple tasks like walking or dressing. I want them to know to not give up and dream big. I race to give them a voice and to give a face to CMT. Despite our challenges we all have ways to achieve victories! Racing gives me hope and a reason to keep being active.

## Dawn Edmiston

I'm Dawn Edmiston, 33, from Scotland.

I was diagnosed with CMT as a baby.

This photo was taken on the top of the Carrick hills on the Ayrshire coast in the middle of lockdown. It symbolises the achievement of feeling at the top of the world even if

you've used splints and two sticks to reach the top. It says to me that with the use of aids we are more able not disabled by our need to use them.

I also love that it was taken during lockdown when we are supposed to be staying away from crowded places, and in this photo it shows the beauty of our environment.



## Lisa Mormann

My name is Lisa Mormann from Dyesville, Iowa. I am 47 years old. I encounter a lot of issues with walking, balance, sensation, coordination, sprained ankles and broken bones. I was always last getting picked for sporting events due to my health. I was first diagnosed with CMT in my 20s.

Twenty years ago when my neurologist at the University of Iowa told me I need to do something to stay active and keep my weight down. That afternoon when I got home I went to my bike shop and purchased my first bike. That was July 5, 2001. Since averaged roughly 8,000 miles a year. Since I've gotten into winter fat biking and gravel racing avoid them Midwest I

have completed the 100 mile of Dirty Kanza 3 times, Gravel Worlds, Filthy 50, The Epic, Barry Roubaix and The Iowa Gravel Classic 100 miles with 10,000 feet of elevation gain. Sterile Iowan pool 150 miles, Rock n Roll (a mudfest), Snaggy 105 and Gravel Monster of MMR roads.

I MAY HAVE CMT BUT IT DOESN'T HAVE ME



## Marjorie McIntosh

CMT is not going to stop me going to the beach!



## Cathy Power

My name is Cathy Power and I am a multi-instrumentalist, singer, and actor. I developed CMT symptoms later in life. Having CMT means that we have had to adapt. I can no longer play the kick drum, so I have had to pass that off to another bandmate. I have to sit to play marimba. I have to take medication to manage tremors before playing, but I am fighting hard to keep playing.



## Filippo Genovese

### ADL

Activities of Daily Living (ADL) like opening a jar, buttoning a shirt or zipping your trousers, using cutlery or a pair of scissors are so frustrating or even impossible when you have Charcot-Marie-Tooth.

Patients should all ask for help and use tools to make these activities possible and gain back their independence.



## Karina Wilgeroth

Having CMTIA is always a battle, pain and tiredness, lots of operations and lots of doctors not knowing what CMT is. It's good to remember everyone has varied effects on their body. I don't let it beat me, there is always a way around things. I am creative in lots of different ways my hands are weak but actually I love painting with fingers and mouth. Anything is achievable and I look at it as CMT made me . I would love to spread knowledge of CMT. Without CMT I would not be me.



## Lacie Tucker

CMT will not and does not define me, I am more than my disability, I am beautiful and I am brave.





## Michael Watkins

This photo of me was taken after I finished in 2nd place in my age group, in a very muddy edition of the Big Ring Challenge 6 hour Mountain Bike Race in North Carolina. I have severe atrophy in my legs from CMT so I had a pair of custom AFO'S made for me to wear when I ride my Mountain Bike. Walking with CMT is very hard for me but I love to ride and race my bike against more able bodded cyclist to prove that you are stronger than you think you are.

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## Nina Antonopoulos

Living with CMT means rolling with the punches- or in many cases, the falls. It is challenging to constantly fight with parts of your body. Sometimes you feel strong enough to try a new activity, here for example I was snowshoeing for the first time and it was rough on my ankles. I listened to my body, collapsed in the snow and joked about how it was a large ice pack. CMT is difficult, and you do fall a lot, but I have found that I got the most out of life after getting back up. The adventure doesn't end with this illness.



## Daniela Soto

CMT does not stop me. I enjoy my life every day, I feel blessed. CMT type 1A.



## Steve Sharp

Hello, we're the Sharp family! Here's us on a family day out to the beach with our dog, Lexi. Something most can take for granted, however, for us it's not that straight forward. We love adventure and the outdoors, no way was CMT putting a stop to that. We love a challenge so that's when the fundraising began! 1800 running miles later and a punishing visit in the boxing ring please meet Lewis' wheelchair and freewheel. Together we are stronger.



## Mozhgan Chalambari

I've had CMT4A from the age of three (wheelchair bound for three years / level of care 4)

"You can't change the wind, but you can set the sails differently".



## Kilian Pauthner

I am Kilian Pauthner and diagnosed with CMT since early childhood. I am also transgender.

Life hasn't always been easy with this but I cope with trying to be my best self. Questioning society's beauty standards and normative way of thinking about human bodies is as important to me as playing with them.

For me, this is a challenge accompanying me my whole life because life is ever changing and so are the challenges to overcome. As adult I learned that being in contact with other people of your marginalised community helps us heal and overcome a lot.



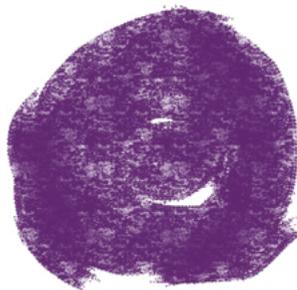
## Ashley McLeroy

I compare myself to those my age who can do more than me. I compare myself to those older than me who can do more than I will. I compare my current self to my younger self and the things I can no longer do. But I'm on a mission to change that. Not only do I want to see others show kindness to those with disabilities but I also want to show kindness to myself. There may be things I can't do but there are so many things I CAN do and I'm proud of that.



## Mara Di Silvestre

A normal February day for someone... and for someone else. My secret is: live a season forward!



## Elisabeth Guillebaud

“My own strategy?

Give me a shiny black expression piano, a dream, and resume the piano! (20 years of conservatory in my youth helped me there).

I muscle myself from both hands continuously, for hours.

And I operate the hand / foot coordination, stretching the Achilles tendon by pressing the Sustain pedal, while working the neurons, memory and the ear.

The piano is my musical gym!

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I have CMT A1, inherited from my disabled father.

I feel the muscle loss in my hands and feet ... “



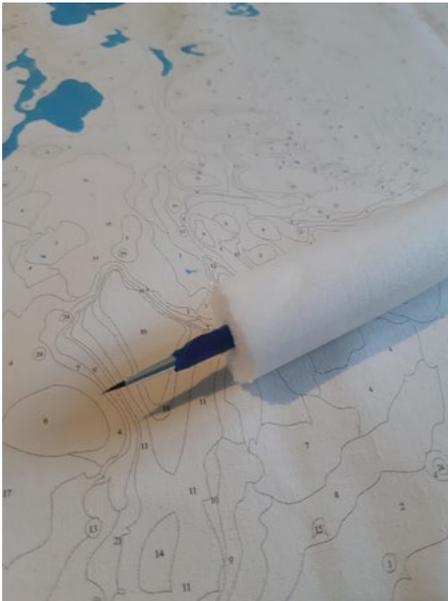
## Lewis Sharp

Me & CMT - the jar contains words to create an image of some of the different struggles I have living with CMT. I find opening jars difficult; I used the jar to represent their place in me. Together we are stronger.

## Lonna Henry

I try to show others it's OK to struggle while living with Multiple Chronic Illnesses as long as you keep smiling and fighting! I have to fight through physical and emotional pain everyday. Living with CMT has shown me how to really be a strong individual inside and out.

I have been sharing my story on Tiktok and I recently won a Bravery Crown.



## Jennifer Owen

I'm very crafty and don't want to let CMT stop me enjoying that, so I adapt! Foam tubing so I can hold the thin paintbrush.



## Jeannette Heibel

CMT or HMSN has been with me almost my whole life, as I started to experience symptoms when I was about 5 years old.

Particular challenges in my life are, of course, mobility, but above all the transport of objects, shopping, luggage, etc. I can neither carry heavy things nor do I have my hands free due to my walking aids. My trike has electric assistance and makes my everyday life much easier. For example, I use it to go shopping or go on bike trips with the family, which I couldn't do with a normal bike. It also helps me to stay as fit as possible.





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