

LIVING WITH CMT

RARE DISEASE DAY 2022

ART COMPETITION

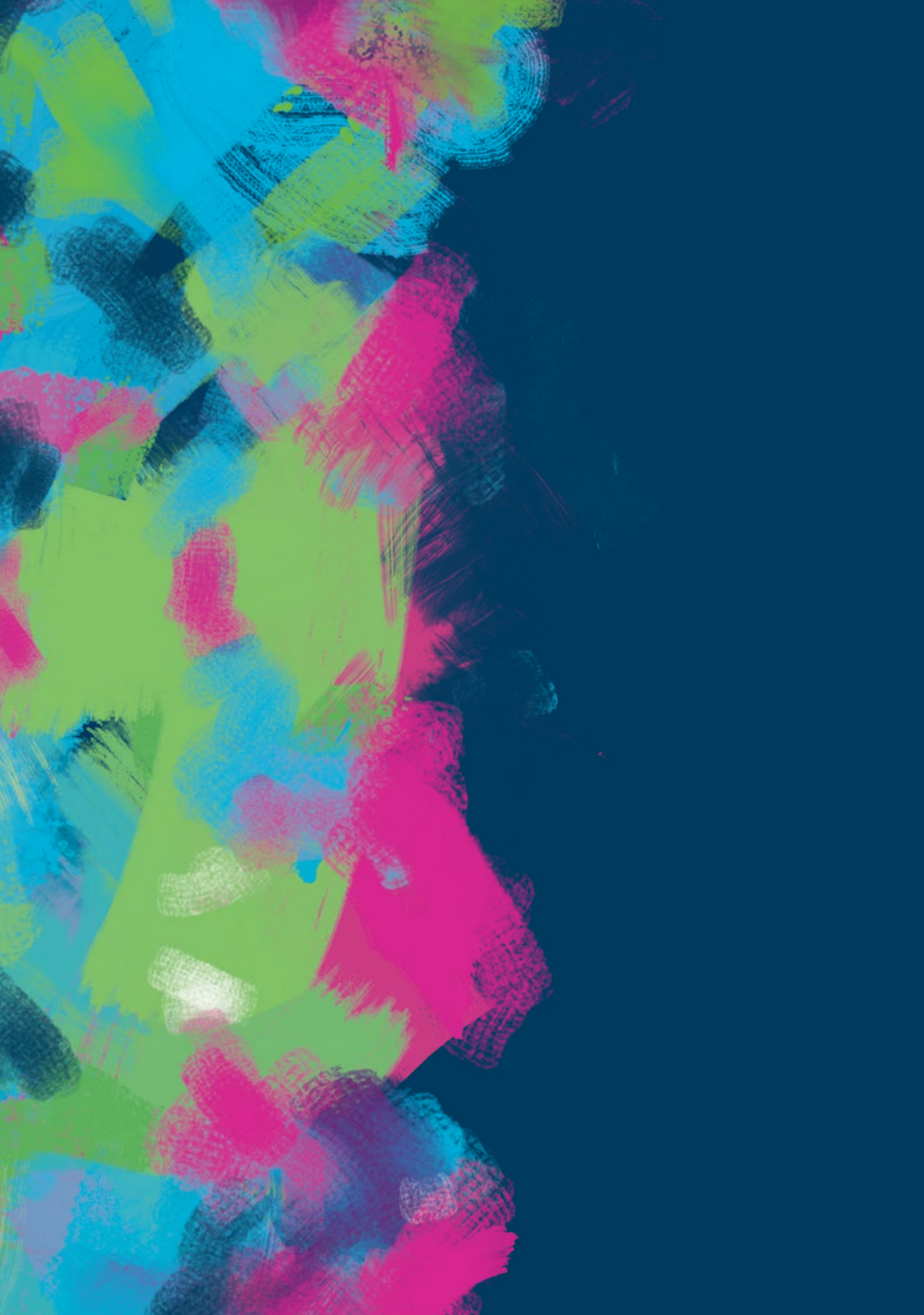


HEREDITARY
NEUROPATHY
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LIVING WITH CMT

ART COMPETITION

To mark Rare Disease Day 2022, the “Living with CMT” Art 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 Charcot-Marie-Tooth disease (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 Elainah, Fabiana and Tina in the over 16 years category, and Tanuj, Elizabeth and Skanda 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 “Living with CMT” Art 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 Patient Advocacy Groups (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 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.

LIVING WITH CMT

WINNERS & FINALISTS

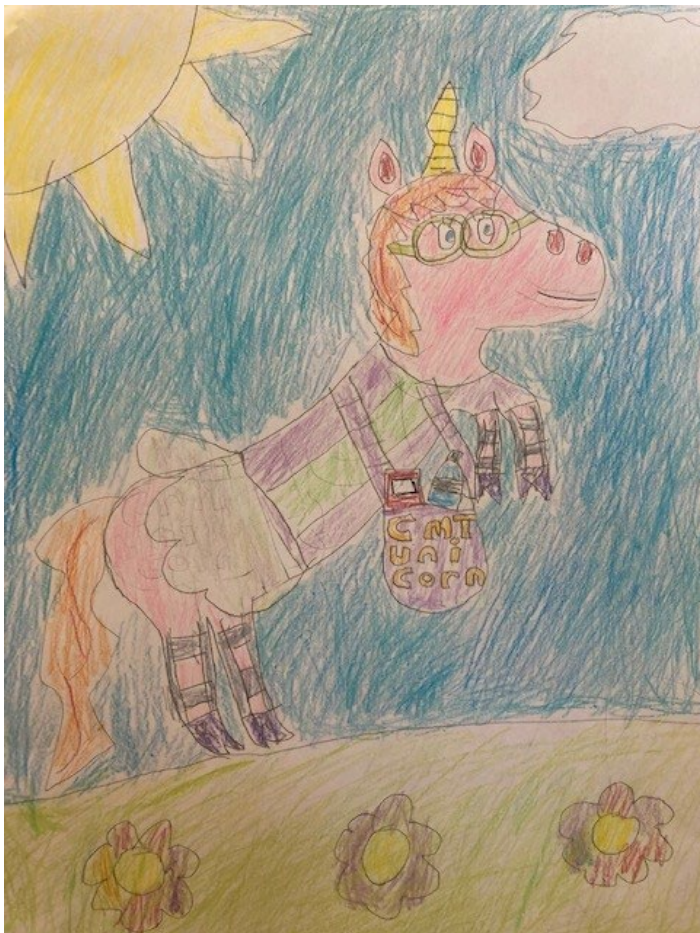


1ST PRIZE Under 16

Tanuj Samaddar

Age 16
India

In my artwork I've shown various challenges a CMT patient has to face and the ways to overcome such challenges. There are therapies and devices such as braces and splinters to make proper use of to get rid of this disease. The news that trials on CMT1A have begun generated hope. I've also shown in my artwork that people suffering from this disease have excelled in various fields from time to time and they have outperformed fully abled individuals. I've also exhibited how positive attitude helps people to live with CMT every day. Adapting to overcome any obstacle one faces is how one should move forward.



2ND PRIZE

Under 16

Elizabeth

Age 12
US

My picture is of a CMT unicorn having a great day enjoying a walk in a field of flowers. She wears arm and leg braces and makes sure to carry her medicine and a water bottle to help her legs not feel a lot of pain. She is very happy and loves to go on adventures and tell everyone about CMT so she can spread awareness.



3RD PRIZE

Under 16

Skanda R

Age 13
India

In my artwork I wanted to highlight the terrible feeling that CMT patients go through. Since getting diagnosed with CMT can be discouraging, frustrating and sadness as others may have to work more and they can't.



1ST PRIZE

Over 16

Elainah

Age 32

Halifax West Yorkshire

I've entered this competition for my husband and two children who are all CMT type 1a.

We never knew it was a something that could be passed through genetic to our children, after being brush off for a long time from the go we finally got answers and since then two of our 4 children so far are diagnosed we believe our youngest also has it but are waiting to see what support he needs.

My eldest son is the worst affected and it breaks my heart seeing him in pain how he handles testing and all his appointments he never ceases to amaze me with the strength he shows daily and how he helps his younger sister, his dad teaches him that even with the condition nothing is impossible! He's an amazing father he pushes himself past this condition, they all are truly CMT warriors and I wouldn't change them for the world.

This image is each of their feet all at different stages of CMT, my son 8, dad 33, and daughter 2.



2ND PRIZE

Over 16

Fabiana

Age 51
Italy

In spite of everything

Dedicated to a fraternal friend, this describes the tree of life, represented by an intertwining of hands that give each other strength and continue to work despite the difficulties! Hands that like roots in the earth seek the connection with their ancestors; hands that like a

throne transmit solidity in a real dimension, hands that like branches and leaves rise towards the sky, almost wanting to stop it, pushed towards the future. The meaning of the work is that you are not alone, since every situation is and will always be connected with the surrounding world.

Nonostante Tutto

Questa orera, dedibata ad un amico fraterno, descrive l'albero della vita, raffigurato da un intreccio di mani che si danno reciprocamente forza e continuano a lavorare nonostante le difficoltà! Mani che come radici addonella terra acercare la connessione con i propri antenati; mani che come troneo trasmettono la solidità 'in una dimensione reale' mani che come rami e foglie si ergono verso il cielo, quasi a volerlo toccare, sospinti verso il futuro. Il significato dell'opera è che non si è soli, poiché ogni situazione è e sarà sempre connessa con il mondo circostante.



3RD PRIZE

Over 16

Tina

Age 54
US

This piece is titled "Maggie's Dream" because every child or adult should have the chance to reach for and achieve his or her dreams without obstacles or fear of failure but with hope and support.



LIVING WITH CMT

RUNNERS-UP

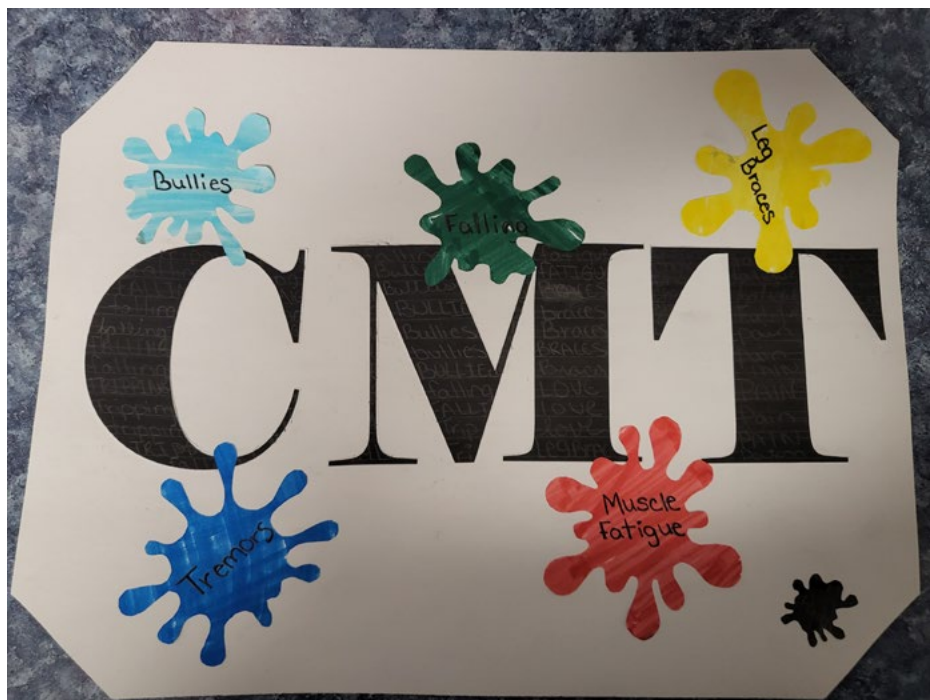


Elena

Age 6
Spain

Drawing made by my granddaughter Elena Vazquez Romero when she was 6 years old for her mother and I embroidered with colored threads.

Under 16

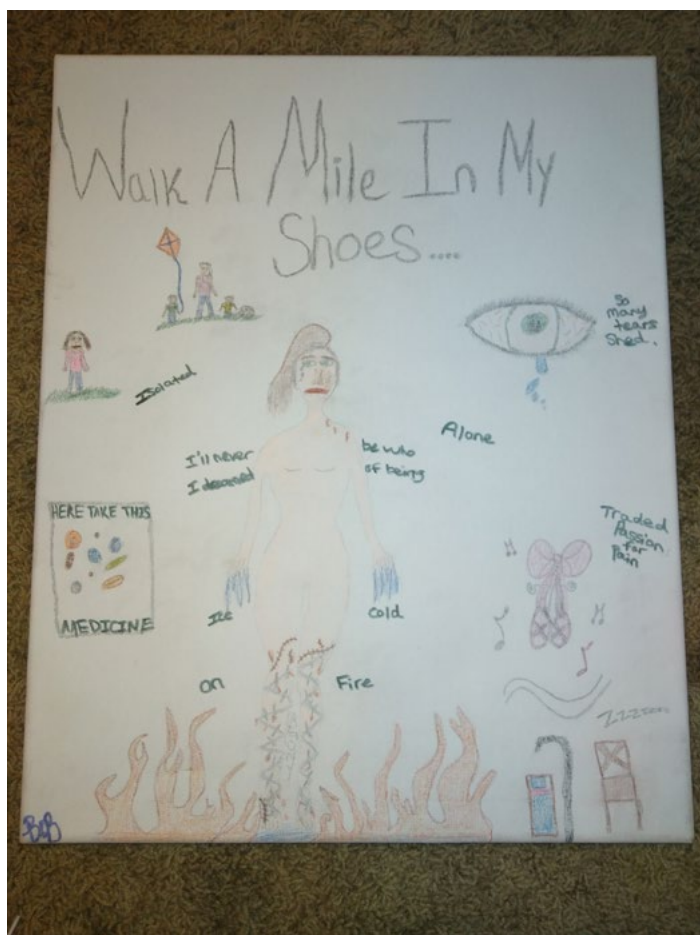


Wyatt

Age 10
US

Under 16

I think life with CMT is hard sometimes. But I have been blessed with family support. Also I have been able to meet cool people. I was diagnosed at 5, but I don't remember not having it. I would not be who I am today without CMT and I would not change it. One day I hope I can help others with CMT.



Brandy B

Age 31
US

Over 16

I'm either as cold as ice or I feel like I'm on fire. Stitch after stitch, cut after cut my legs are left to heal on their own. I traded my dance shoes and passion for pain and a cane. The tears I've cried because of CMT could overflow the Ocean. I'm forced to sit on the sidelines and watch everyone else enjoy the fun things in life with my children. I am told every pill has a purpose but I'm not convinced. Because of CMT I am not the woman I dreamed I'd be, I am merely taking up space.



Kaileen

Age 30
Greater Vancouver

Sometimes, having CMT can make you want to curl up and hide away. However, there's a unique strength you possess when you live with CMT. Realizing how capable you actually are, is a beautiful thing.

Over 16



Henriette

Age 37
Norway

Over 16

Tension in hand is a painting of my hand as it struggles to grasp a rhododendron bud. It represents the sensation and emotion connected to struggling with hand function: The physical tension that grips my hand and the emotional tension gripping my mind.



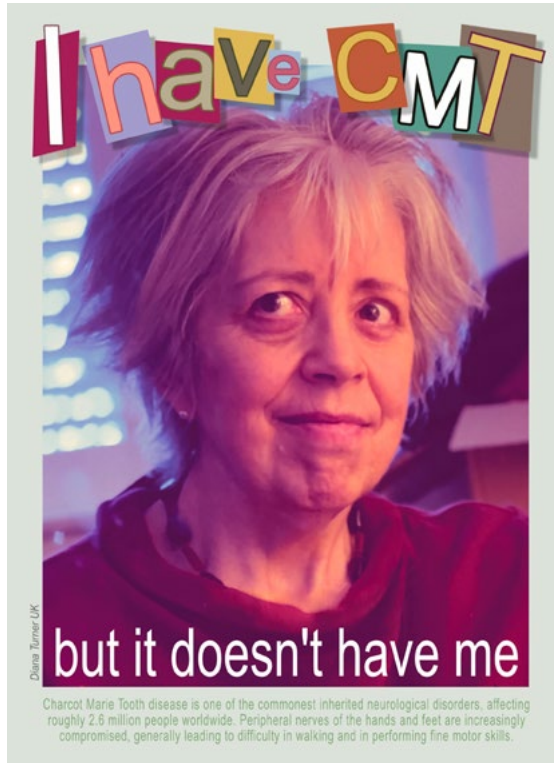
Lorenzo

Age 34
Italy

Over 16

The work "Of me is not afraid" is a cartoon that I made this year. I am a boy with type 2 CMT, and I wanted to represent, through a positive message, the life of a disabled person in a wheelchair. The protagonist is me, who have a dialogue with work and illness, you see work that "eats" all my free time, I who have a quarrel with it, and the disease put in a corner that he says, "He's not afraid of me." I wanted to send a positive message about how the disease is cornered despite the difficulties and the hectic life (despite smartworking and disability).

L'opera "Di me non ha paura" è una vignetta che ho realizzato quest'anno. Io sono un ragazzo affetto da CMT tipo 2, ed ho voluto rappresentare, tramite un messaggio positivo, la vita di una persona disabile in carrozzina. Il protagonista sono proprio io, che ho un dialogo con il lavoro e la malattia, si vede il lavoro che "mangia" tutto il mio tempo libero, io che ho un battibecco con lo stesso, e la malattia messa in un'angolo che gli dice "Di me non ha paura". Ho voluto lanciare un messaggio positivo di come la malattia venga messa all'angolo nonostante le difficoltà e la vita frenetica (nonostante lo smartworking e la disabilità).



Diana Turner

Age 66
UK

Over 16

I was diagnosed aged 26 and have worn ankle-foot orthoses for 40 years.

The challenge: to survive as a single woman with a hereditary and physically demanding disease.

The strategy: to relocate to London, begin a second career and to stick to a positive mindset.

The result: an amazing career, becoming an editorial director, buying a flat, finally marrying and gaining a ready-made family. In retirement I have begun painting in oils, holding the brush in a fist. Time constraints prevent me from submitting one of these to meet the brief.

Please accept my poster as a submission for consideration.



Vittorio

Age 77
Italy

Over 16

I'm Vittorio Ferrarini, a former entrepreneur now retired, and I live in Parma. I recently joined your Association. Exactly on January 20 of this year.

My pathology began around the year 2000 but only recently, thanks to a physiatrist friend, did I "discover" its origin and name.

Thanks to your Scientific Referent, Filippo Genovese, dear person who recently visited me, I learned about this competition.

The work has nothing to do with

pathology but the power to paint despite the difficulties due to the lack of "pliers" of the hands, gives me a lot of comfort and relief, helping me a lot to overcome this problem.

To find out more, just go to my art site.
www.vittorioferrarini.it

Sono Vittorio Ferrarini, ex imprenditore ora in pensione, e abito a Parma. Recentemente ho aderito alla vostra Associazione. Esattamente il 20 gennaio di quest'anno.

La mia patologia inizia circa nell'anno 2000 ma solo recentemente, grazie ad un amico fisiatra ne ho "scoperto" l'origine e la denominazione.

Grazie al vostro Referente Scientifico, Filippo Genovese, carissima persona che recentemente mi ha fatto visita, ho saputo di questo concorso.

L'opera non ha nulla a che vedere con la patologia ma il potere dipingere nonostante le difficoltà dovuta alla mancanza di "pinza" delle mani, mi dà molto conforto e sollievo aiutandomi non poco a superare questo problema. Per saperne qualcosa in più basta andare sul mio sito dell'arte.
www.vittorioferrarini.it



Rita

Age 67
Belgium

Over 16

CMT goes on and on so that our muscles slowly lose strength.

The expression of this work is life in the maize: the strength we still have.

And glass that can only stand still: like the muscles where the strength is gone.

The image after the word: still life.

CMT gaat steeds verder zodat onze spieren langzaam kracht verliezen.

De uitdrukking van dit werk is het leven in de mais: de kracht die we nog hebben.

En glas dat enkel stil kan staan: zoals de spieren waar de kracht weg is.



Katiuscia

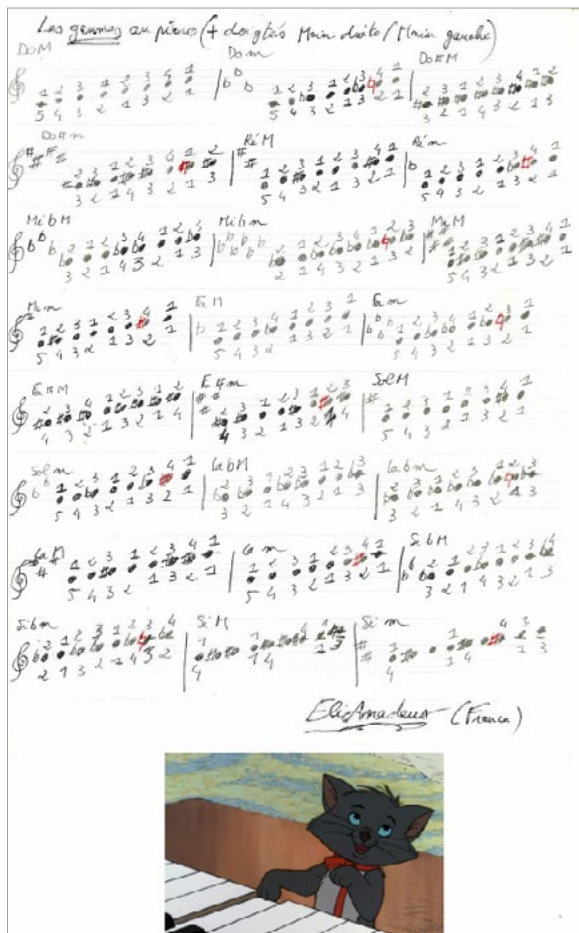
Age 48
Italy

Over 16

Title of the work: La Libertà.

This design is a bridge in the middle of nature. I chose this design because no one is different there on that bridge, there are no differences, there are no architectural barriers to face. There is a place where both us with CMT and other people do not exist, we are all equal and free. Freedom is the most important thing in life. But unfortunately not everyone in real life is, I'm not because I always need help. There instead on that bridge they are indeed we are all free.

Questo disegno è un ponte in mezzo alla natura. Ho scelto questo disegno perché lì su quel ponte nessuno è diverso. Non esistono diversità, non esistono barriere architettoniche da dover affrontare. Lì è un posto dove sia noi con cmt che le altre persone non esistono differenze, siamo tutti uguali e liberi. La libertà è la cosa più importante che ci sia nella vita. Però purtroppo non tutti nella vita reale lo sono, io non lo sono perché ho sempre bisogno di essere aiutata. Lì invece su quel ponte sono anzi siamo tutti liberi.



Elisabeth

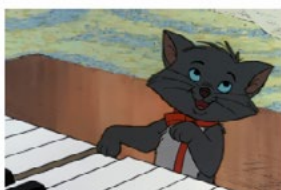
Age 45
France

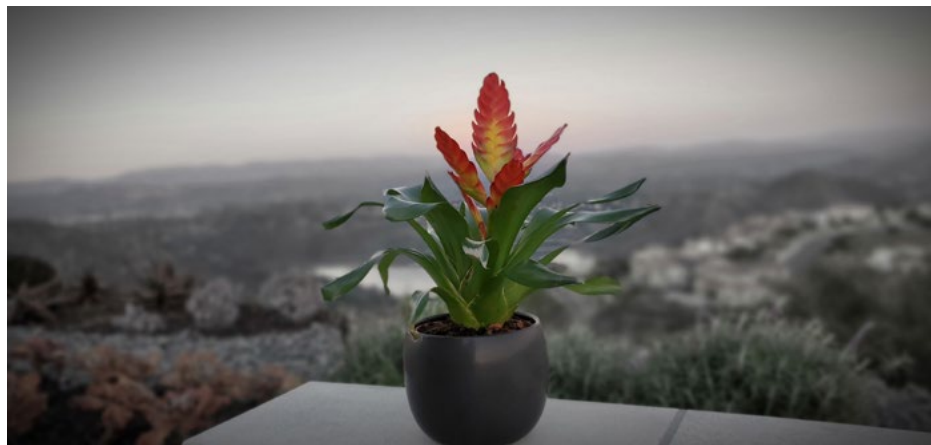
Over 16

Being left-handed... and CMT XI patient... doesn't help to write nicely!

But, and I can't explain it, when I write music notes, suddenly everything is easier!

My art strategy: I play the piano, write sheet music, repeat my scales and my arpeggios, there I become an Aristocat and forget all!





Angela

Age 58
US

Over 16

“Uniquely CMT”

CMT impacts us each uniquely. By tuning out what’s happening in the community around us (from amputations to achievements) and focusing on our own strengths, we can achieve great heights and let our own beauty uniquely shine.



Linda

Age 79
Canada

Over 16

Losing the ability to walk was difficult, losing the use of my hands is even harder. but having to cope with burning neuropathic pain constantly simply digs into my soul. Why can't the fates leave well enough alone and just take my mobility but, no, they have to torment me by making many of my waking hours a burning, living hell. And yet the human spirit claws its way out of pity and pain to rejoice in the new day and the fact that life can still be good.



Annie G

Age 78
USA

Over 16

Take Time to Enjoy

My husband of nearly 60 years has CMT1A but he has never let it interfere with his enjoyment of life. He has always kept a positive outlook, accepting and adapting to changes in his body while staying as active as possible. I painted this image of him walking on the beach with our dogs during one of our many vacations.



WWS
(Woman with stick)
aka
Jan Sargeant

Age 65
England

Over 16

HNPP makes life difficult and daily life can be a challenge, and some days I can't use brushes because of it. So I will use clumps of kitchen roll, sponges, anything at all to make marks. Marks to communicate how I feel. Marks to take me in my mind to places I can no longer get to physically. This is where I go - my place of peace, beauty, tranquility. Where HNPP doesn't exist alongside Parkinson's. This is how I cope. I paint. In paint I escape. Without paint, I know only pain.



Marina C A

Age 17
Spain

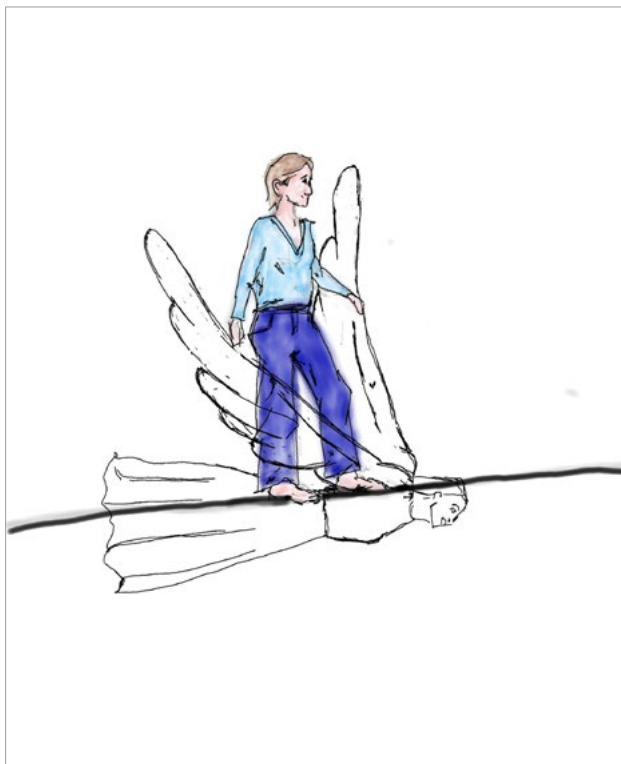
Ay ay ay
What misfortune I have
"mare" in walking
Like the steps that I took forward
they go behind me"

Over 16

Couplet from Baja Andalucia 19th century

Ay ay ay
Que desgracia yo tengo
"mare" en el andar
Como los pasos que p'alante daba
se me van atras "

Copla de la baja Andalucia siglo XIX



Annalisa G

Age 21
Italy

Over 16

Salutations,

My name is Annalisa Grisenti, I am a 21 year old girl.

Thank you for giving me the opportunity to reflect on how CMT affects my life.

I am very pleased to share with you this small part of my life, which accompanies me every day.

I leave attached my drawing, and the completed and signed release.

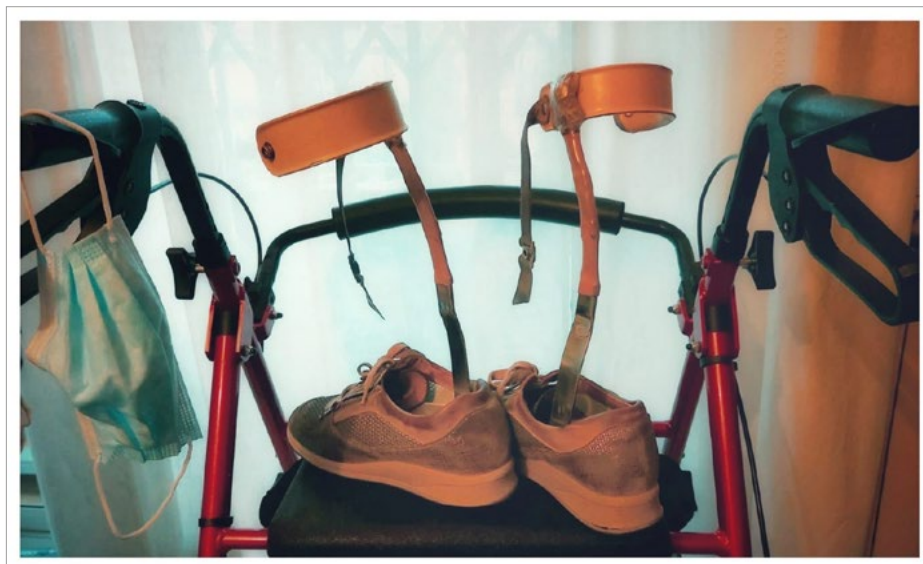
Salve,

Mi chiamo Annalisa Grisenti, sono una ragazza di 21 anni.

Grazie di avermi dato la possibilità di riflettere su come influisce la CMT sulla mia vita.

Mi fa tanto piacere di condividere con voi questa piccola parte della mia vita, che mi accompagna ogni giorno.

Vi lascio in allegato il mio disegno, e la liberatoria compilata e firmata.



Esther G T

Age 20
Spain

Thanks to them I can go for a walk everyday.

Over 16

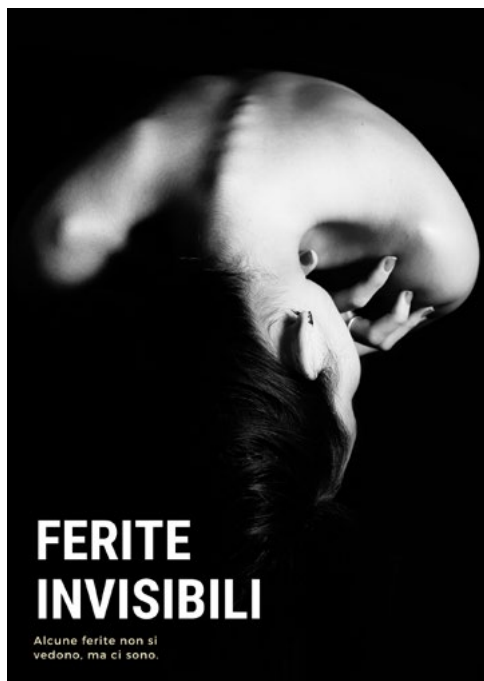
My story has been filled with challenges, bruises, scars and ugly truths. My life has also been filled with major comebacks, and a tremendous will to fight and inspire others. I am a strong woman who refuses to be defeated. I have never been afraid to show my true self, every part of it. There is never any reason to be anything but your authentic self. Real scars are more admirable than fake imperfections. This woman is me. I have CMT4C and I am a CMT warrior.



Victoria H

Age 38
Canada

Over 16



Alice D

Age 23
Italy

Over 16

Although they are two different photos, they should be understood as a single work, one represents the problem and the other a possible solution.

To clarify:

Photo 1: Problem

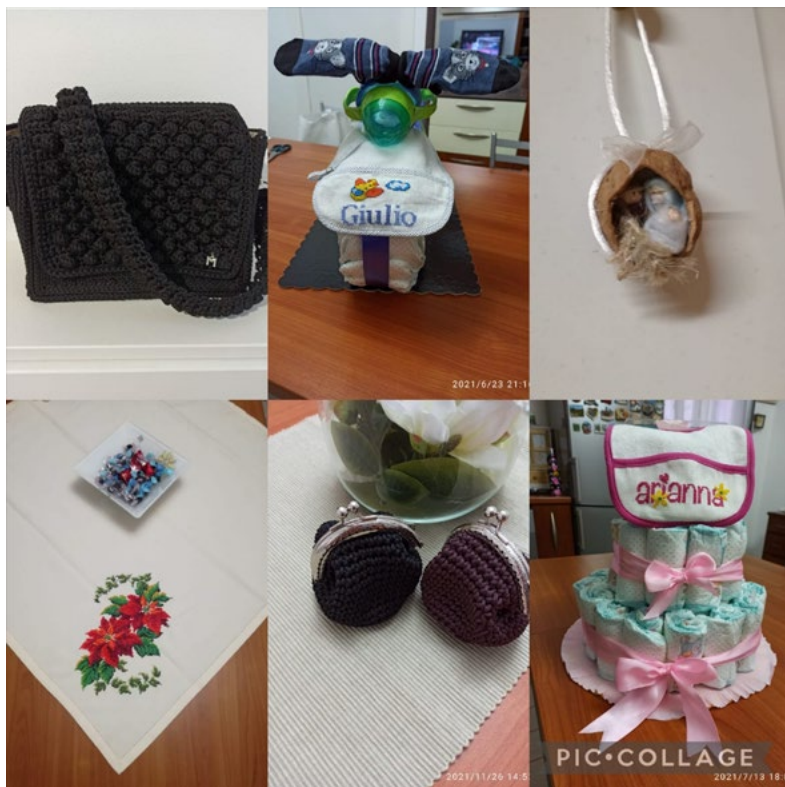
Photo 2: Possible solution

Sebbene siano due foto diverse, vanno intese come un'opera unica, una rappresenta il problema e l'altra una possibile soluzione.

Per chiarezza:

Foto 1: Problema

Foto 2: Possibile soluzione



Lorella

Age 54
Italy

Over 16

My name is Lorella, I am 54 years old and since I was a girl I have had a passion for embroidery. When at 18 the CMT (pathology that compromises the functionality of the lower and upper limbs) knocked on my door, I never allowed her to limit or even make me abandon my passions; indeed, in recent years I have also become passionate about crochet and creative works!

In this period I am doing physiotherapy and the therapist told me that she is almost ashamed to let me do fine manual exercises, because I already do enough on my own; my passion that turns into therapy!

Titolo dell'opera: "Unire l'utile al dilettevole"

Mi chiamo Lorella ho 54 anni e sin da ragazza ho avuto la passione per il ricamo. Quando a 18 anni la CMT (patologia che compromette la funzionalità degli arti inferiori e superiori) ha bussato alla mia porta, io non le ho mai permesso di limitare o, addirittura, farmi abbandonare le mie passioni; anzi, negli ultimi anni mi sono appassionata anche all'uncinetto e lavori di creatività!

In questo periodo sto facendo fisioterapia e la terapeuta mi ha detto che quasi si vergogna a farmi fare esercizi di manualità fine, perché faccio già abbastanza da sola; la mia passione che si trasforma in terapia!



Maura

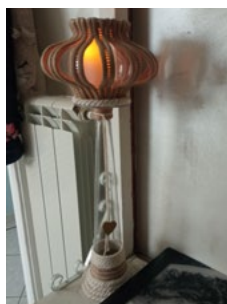
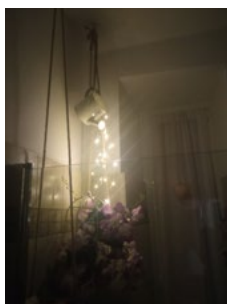
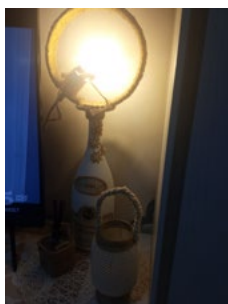
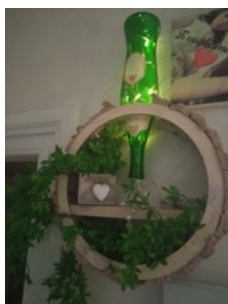
Age 28
Italy

Over 16

IO & CMT Dancing together

In my daily life the difficulties that CMT makes me facing become easier thanks to dance. I have acquired a major awareness and acceptance of my body. And when the music starts, CMT and I become a team.

Nella mia quotidianità le difficoltà che la CMT mi fa affrontare diventano più semplici grazie alla danza. Ho acquisito una maggiore consapevolezza e accettazione del mio corpo. E quando parte la musica la CMT e io diventiamo una squadra.



Stefania

Age 42
Italy

Mine is the passion of recycling, old cans, non-slip mats, ropes and everything comes to life in new forms.

Lanterns or lamps with barter products, anti-slip mats, ropes, old vases, etc.

Over 16

La mia è la passione del riciclo, vecchi barattoli, tappetini antiscivolo, corde e tutto riprende vita in nuove forme.

Lanterne o lampade con prodotti riciccati barattoci, tappetini antiscivolo, corde, vecchi vasi ecc.



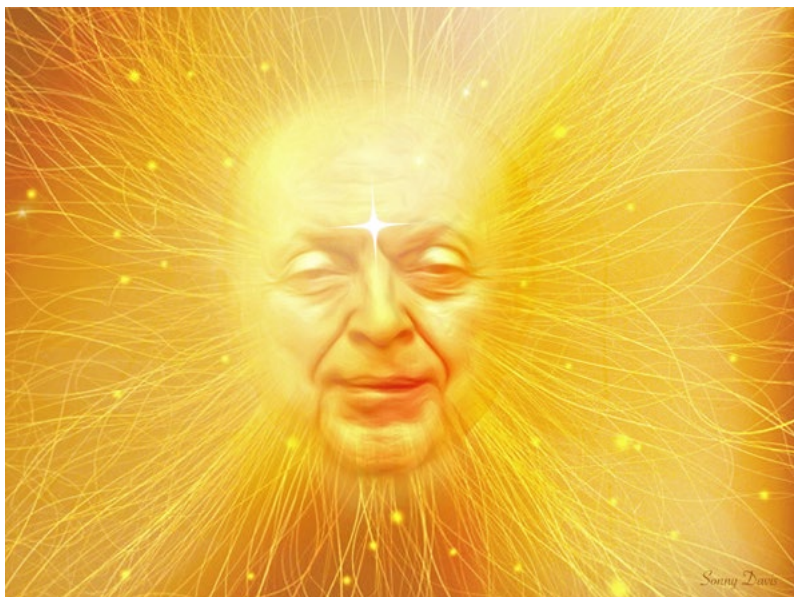
Serena

Age 67
Italy

Over 16

Deformed feet in search of a precarious balance: I stagger, stumble, skid... but I go on! Stable or not, this is my life. Like me, many people get up every day, dress and work, love and care as if their hands and feet were healthy.

Stepping walk, like a pink flamingo... I see them every day in the shining pools of water near home. It's amazing to live in Sardinia, this wonderful land of sea and light, of nature and clean air. This is a gift. A compensation for being different by the normality that is, indeed, a double strength.



Sonny

Age 41
Mexico

Over 16

My name is Sonny. I am 41. I am a Canadian living in Mexico. I experience CMT.

Living with CMT is indeed an interesting evolutionary experience. Life can be either a bitter struggle or a great challenge. It can be so easy to feel small and shrink into one's personal negative internalizations about one's self worth or true nature. Sometimes we need a portrait-reflection of our own divinity as brave warriors and a reminder of the love and light we are, beyond our disabilities and other assumptions we hold most sacred.

I wish for everyone to experience a soulful-beauty in this lifetime.

A soul portrait is an amazing tool to remind you of who you are. Pictures can tell more than words, empowering you and giving you inspiration on your journey.

Through the gift of inspired digital-art as a strategy to empower others and myself; creating purpose and meaning; I mash-create and edit custom, beautiful, vibrant, inspiring, sometimes psychedelic images from any picture or headshot that you wish to have transformed.

These are beautiful and thoughtful, unique and meaningful, fast and easy gifts that help us defuse from the limited perception of ourselves to see the magical and multidimensional aspects of our being.

You ARE a bright, beautiful creative soul, with a unique essence, purpose and vibration.

A soul portrait will help you to connect with your inner beauty and true nature.

A forever gift.

My art submission piece is called - "The Bright"



Lynn

Age 60
US

Over 16



Manu

Age 27

Over 16

I drew this for the group I made with my best friend who also has CMT we made the group so others with CMT can connect with others with CMT and we help each other out with news about adaptive products and or help each other out by helping others with customizing ways to help everyone play games better! It's a Facebook group!

