

# MDA Taaatara | Central Region

## Newsletter – Winter 2023



Kia ora everyone,

Our AGM was held via zoom in April.

It was great to see over twenty members zooming in, and many more tendering apologies.

We were very lucky to have Paula Tesoriero Chief Executive, Whaikaha - Ministry of Disabled People join our AGM as a guest speaker. Members thoroughly enjoyed listening to Paula's speak about Whaikaha and were able to ask questions at the end of her presentation.

AGMs are always a suitable time to reflect on the past year.

Over the past fiscal year MDA Central Region has secured several grants that enable the branch to continue to operate and offer members targeted financial assistance.

We have offered members over 70 in person or online events, our team of fieldworkers and community coordinators have visited members across our region and our membership continues to increase.

At the AGM, three committee members stood down and the committee welcomed two new members on board.

You can read more about your new Executive Committee on page 3 -5 and meet our MDA Central team on page 6 😊

**Did you know,  
donations are always  
welcome via online  
banking or our give a  
little page.**

**Westpac Account:  
03-1533-000617800**

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## THANK YOU

At this year's AGM, three of our Executive Committee Members stepped down.

We would like to thank **Tristram Ingham**, outgoing Chair and life member, **Lyn Hawkins**, life member and **Richard Stein**, outgoing Treasurer for the commitment they have shown during their terms on the MDA Central Executive Committee.

Without Tristram's hard work and dedication during his tenure as Branch Chair MDA Central would not be the thriving, vibrant and inclusive branch it is today.

Under Tristram's leadership membership numbers have grown, member engagement has steadily increased and member satisfaction is at an all-time high.

Tristram spent countless hours behind the scenes securing grants, working on the branch strategic plan, developing the systems we use, and mentoring our committee and staff so they can best serve you.

***Ngā mihi, from all of us at MDA Central***

# Check out these awesome entries in our recent Easter colouring in competition!



Aren't they awesome!



# MEET YOUR COMMITTEE

## (As elected at the AGM held April 2023)



### **John Hawkins (Chairperson)**

I am a retired person these days but have been around disability a very long time now as my wife has “Friedreich’s Ataxia”  
I have supported her on her journey with this condition since we were married in 1970.

It is supporting my wife that has helped me to keep a weather eye on the level of support for people with neuromuscular conditions and their families have been getting over the years.

### **Lydia Wilson (Vice Chair)**

My name is Lydia, and it is my privilege to serve you on the executive committee as vice-chair.

I live with my parents in a wheelchair accessible house. I have Frederick's Ataxia.

I enjoy doing work for the MDA when I am well which should be more often soon. I prepare the faith group once-a-month.



### **Francesca Herdahl-Thorsing (Secretary)**

Hello, I’m Francesca, Secretary of the central branch committee and National Councillor at large.

I have CMT type 1A and run the CMT support group.

I work as an Analyst at the Ministry for Primary Industries in Wellington. I love to travel and speak fluent German.

My fiancé and I are currently trying to decide where to spend our honeymoon after we get married in August this year!





## **Liz Church (Treasurer)**

Kia ora. I'm Liz Church.

I was born and raised in Whanganui as the fifth child in a family of seven. I worked as a teacher for nearly 30 years, two of those in London and 13 in the Coromandel.

After my neuromuscular condition developed, I changed careers and now work in the disability sector as a project coordinator.

Ahuriri/Napier has been my home since 2002 and I love it here.

I have a passion for art, and enjoy music, yoga and spending time with my family and friends.

I recently took up the role of treasurer on the Executive Committee.

I hope the work we do supports you, as members and whānau, to have what you need, to live the lives you want.

## **Alison Riseborough**

I joined MDA in 1980 after being diagnosed with FSH.

I was first on the committee in the 1980s and 1990s when we were a small struggling group with a minimal bank balance (and before the Internet was born). I was happy to re-join the committee 3 years ago – made possible by Zoom meetings.

The region has grown amazingly in size and inclusiveness.



## **Joel Latimer (co-opted member)**

I connected to MDA Central through a whanau member with a condition, I've been actively involved with MDA Central over the past 6 years, utilising my expertise to contribute to the organization's mission.

I am a seasoned IT professional with 12 years of experience in IT management and solutions.

## **Heidi Beuth-Lepper**

I'm Heidi from Gisborne. I'm privileged to be part of the MD Executive Committee for our region. I have two wonderful children I'm so proud of Georgia 25 who is a Neurodevelopmental Therapist / Occupational Therapist in Hamilton and Jack 21 who has just graduated with a Health Science Degree at Victoria.

My amazingly supportive Husband Dave is the Seeka Packhouse Manager here in Gisborne. We all have fantastic support from my amazing Mum who also has MD.

In Gisborne I've had various Logistic jobs, Production Planning and Livestock coordination but then due to decline vision and health I had to medically Retire at 42, nine years ago. I have a rare Maternally Inherited Mitochondrial Myopathy and Neuropathy with Optic Atrophy, but it is what it is mindset 🌸



## **Monique Tawhiri**

My name is Monique Tawhiri.

I was born and raised in Auckland however I currently live in Napier with my husband Rick and daughter Aroha.

Prior to my MD symptoms I worked in various sectors such as the Defence Force, private medical practice, and education as an administrator.

I believe my role is to provide support for our members and their whānau.

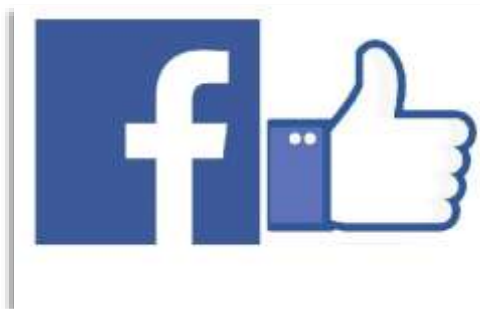


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**Our Facebook page continues to be the tool we use to get information to you quickly.**

**It has been especially helpful for our East Coast members since Cyclone Gabrielle.**

**We have been able to share accurate and up to date information on the recovery in our Hawkes Bay members group.**



**You can follow us using the link below, do not forget to give us a like!**

<https://www.facebook.com/MDACentralRegion>

## Meet the MDA Central team



### Talitha Vial – Fieldworker

I'm your central fieldworker Talitha Vial,  
I'm the one that will turn up at your place with a smile.  
I live in Pahiatua out in the middle of nowhere.  
I have Myasthenia Gravis so understand and truly care.  
Let's meet and catch up.  
I like my coffee in a takeaway cup.

### Cherie Fredrickson – Talitha's support

Kia ora,

I would like to officially introduce myself for those of you who hear my voice but don't meet me.

My name is Cherie Fredricksen I reside in Pahiatua and am married to David, a lovely man and he works as a paramedic for St John. I've been married to David for 32 years and have 3 adult sons which keeps us loving our alone time.

I have an understanding of disability having been diagnosed with a condition at 18 years of age, I too have to regulate my days. I have a family member with muscular dystrophy, so this role suits my experience.

I am a vibrant, positive personality and enjoy being a support for Talitha so feel free to say Hi when I ring you up to book appointments, invite you to an event or anything else I may do at the time.



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**Have you recently moved house, changed your phone number, or email address?**

**Please let us know your new details:**

**0800 886 626**

**or**

**[members.central@mda.nz](mailto:members.central@mda.nz)**

## CMT Study - an update from Adam Philps, podiatrist.

*Following on from Adam's interesting article in our last newsletter. Adam has kindly supplied us with the abstract for the study.*



### **3D-printed custom ankle braces for people with Charcot-Marie-Tooth: a pilot study**

Adam Philps 1  
Mike Frecklington 2,3  
Sarah Stewart 2,3

1. Masterton Foot Clinic, Masterton, New Zealand
2. School of Clinical Sciences, Faculty of Health and Environmental Sciences, Auckland University of Technology, Auckland, New Zealand
3. Active Living and Rehabilitation: Aotearoa New Zealand, Health and Rehabilitation Research Institute, School of Clinical Sciences, Auckland University of Technology, New Zealand

#### **ABSTRACT**

**Background.** Charcot Marie Tooth (CMT) is an inherited progressive neurodegenerative condition that can result in drop foot, changes in balance, and walking impairment. 3D-printed custom ankle braces are designed to improve ankle joint function and lateral ankle stability, however, their use in people with CMT has not been explored.

**Aim.** The aim of this feasibility study was to determine whether a 3D-printed custom ankle brace improves function and balance in people with CMT, and whether the device was acceptable for use in this population.

**Methods.** A 4-week intervention study was undertaken, recruiting people with physician diagnosed CMT in the Wellington region of New Zealand. All participants were fitted with a pair of custom ankle braces. Functional walking and balance tests, and patient-reported foot pain, disability and falls history were assessed before and after the intervention. Participants kept a daily diary recording hours worn and any adverse events. Patient-reported acceptability of the device was assessed post-intervention. Data were analysed using linear regression and results were adjusted for hours worn.

**Results.** Eleven people with CMT were included (mean age 48 years, 60% male). A statistically significant improvement was seen during single leg balance with eyes open ( $P=0.026$ ) and a significant reduction in foot pain ( $P=0.045$ ), following use of the ankle brace. Participants were moderately satisfied with the look and comfort of the brace.

**Conclusion.** A 3D-printed custom ankle brace may be an effective and acceptable therapeutic option to consider for some people with CMT who have foot drop and/or instability.

# Please enjoy some original writing from Gisborne member: David Callaghan

## Kingdom Hearts II - Axel Meets Kairi

Maybe... waiting ins't good enough.

My thoughts exactly! If you have dream, don't wait. Act. One of life's little rules. Got it memorized.

who are you?

Axel, I happen to be an acquaintance of Sora's. Why don't we go see him?

... Sora?

We've got something in common, Kairi. You and I both miss someone we care about. Hey... I feel like we're friends already.

You're not acting very friendly!

You okay... you and that dog came flying out a hole in the wall you almost gave us heart attacks.

## Kingdom Hearts 358/2 Days - Xion And Axel Face Off

Why do I always get stuck with the icky jobs?

....Axel...

Xion...what are you gonna do?

I've decided that I have to go back to where I belong.

Well, to be honest, I always felt that was best, right from the very beginning. But you know, it still really bugs me. Something about this just stinks.

It's for the good of everyone.

But how do you know that? Everybody thinks they're right.

This IS right.

They're going to destroy you.

Please don't hold back, Axel. Promise.

WHAT IS YOUR PROBLEM? You both...think you can do whatever you want. Well, I am sick of it. Go on, you just keep running. BUT I'LL ALWAYS BE THERE TO BRING YOU BACK

## The Executive Committee need your help!

The central branch has a wheelchair accessible van, which is currently not getting as much use as it could.

The Executive Committee would like to put a call out to the members for ideas of how we could make better use of the van.

Send an email through to [secretary.central@mda.nz](mailto:secretary.central@mda.nz) and give us your ideas.

**Ngā mihi**

**Your Executive Committee**