The newsletter of the Charcot-Marie-Tooth Association of Australia Incorporated, providing information and support for people with Charcot-Marie-Tooth disease and their carers, health professionals and friends.

VOLUME 92 Winter 2019

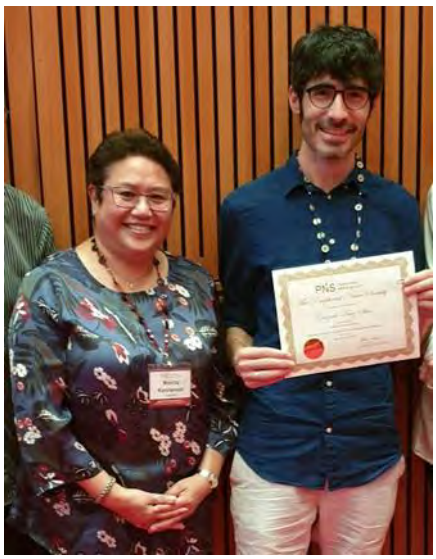
CMTAA
Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

AUSTRALIA'S ANZAC INSTITUTE SHINES

Peripheral Nerve Society (PNS) MEETING

Members of the Northcott Neuroscience Laboratory at the ANZAC Research Institute have recently returned from the 2019 Peripheral Nerve Society (PNS) conference held in Genoa Italy in which the teaching contribution of Associate Professor Marina Kennerson and the research of Postdoctoral Fellow Gonzalo Perez-Siles has been internationally praised and acknowledged. The PNS conference is the key international meeting for peripheral nerve disease research and includes the largest gathering of researchers working on CMT and related inherited neuropathies.



Associate Professor Marina Kennerson and Dr Gonzalo Perez-Siles at the PNS Meeting in Genoa, Italy last month.

Associate Professor Marina Kennerson who leads the Gene Discovery and Translational Genomics Inherited Neuropathy Program at the ANZAC Research Institute was invited to present in the Education Session of the PNS meeting. The goal of this session is to provide conference attendees with the latest ideas and cutting edge technologies and research strategies for peripheral nerve disease. Associate Professor Kennerson's expertise was sought by the Education Committee to provide an overview of the next generation sequencing technologies and gene mapping tools (genome wide association studies) being used to unravel the genetics of CMT and related inherited neuropathies. "My talk focused on providing didactic examples from our most recent research discoveries that not only demonstrated the application of these exciting tools but also provided insight into how we can tackle the diagnostic problem of finding the genetic cause for the remaining unsolved families (which can be up to 40% after screening for known genes)" said Associate Professor Kennerson. Her presentation was one of six talks given in the teaching session. The lecture was given to hundreds of young investigators and was widely recognised as the highlight of the entire training program. A key message of Associate Professor Kennerson's talk was the importance of looking beyond gene coding mutations and using structural variation (large DNA re-arrangement) analysis to solve genetically undiagnosed families. "Having our research strategy highlighted in the Presidential Address at this meeting is a testament that our work is having a significant impact on the direction of CMT gene discovery for unsolved families" said Assoc Professor Kennerson.

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INSIDE THIS EDITION

Our greatest glory is not in never falling but getting up every time we do—Confucius

PRESIDENTS REPORT

My fellow CMT'ers

Welcome to winter! I hope the cold weather is exacerbating any of your aches and pains too much, Don't worry – only a few months to go!

My wife Angie and I am really looking forward to meeting as many of our Victorian CMTer's (and those who will travel) at our Annual seminar in Melbourne on 21 September. Paula and the Victorian team have arranged a great line-up of speakers and I am sure this will be a informative day and a great way to connect. We always get fantastic feedback on the value of our seminars and I would urge as many of you who can to attend.

As we are at the half way point in the year I thought I would provide an update on the activities of your committee:

We are continuing to work on developing a marketing plan (as a key priority in our strategic plan) to help get the CMT message out there. Stage 1 of the plan will be focusing on how we get our message (we are here, we can help, we are a great source of CMT information) to the medical and allied health communities. We have all visited a doctor/physio/podiatrist who has looked at us blankly when we mention we have CMT. We want to address this, raise awareness of CMT and CMT Australia and help newly diagnosed CMTer's get the help they need

Lisa is driving a project to update and upgrade our web site so that it provides a new look and improved functionality and access to important resources

We have received a government grant of $1,300 to allow us to update some of the furniture and fixtures in our Sydney office. New ergonomic chairs for our office team are number one on our list.

To improve collaboration across organisations like ours, I have joined the Board of Genetic Alliance Australia

While the donations received in 2018/19 are yet to be fully tallied we have again raised a significant amount to assist with research into the cure and treatment of CMT. While we have probably not raised enough to fully fund all the requests for assistance we have received I want to thank you all for your generosity and fundraising activities. This is a vital component of our role as an Association and I would welcome any ideas from members for additional fund raising opportunities.

The document from CMTA USA we were able to share with members has proven immensely popular. This publication outlines the assessment and care of people with CMT. As CMT manifests so differently from person to person, this guide, based on research, experience and patient input, will optimize collaboration between physical and/or occupational therapists and patients, helping ensure you get the best possible care for your specific needs. I urge you to take a look and share this document if you haven't already. It is available on our website.

Hope to see you in Melbourne. Be kind to yourself.

Tony

NEWS FROM THE REGIONS AND STATES

TASMANIA

David and I spent 7 weeks touring Victoria and outback New South Wales. It was lovely to catch up with fellow CMT folk in Deniliquin and be shown around their town. Thanks Denise and John – we loved it. We then headed further north and were saddened by the evidence of their worst drought – the poor Darling River just a puddle of green slime! The resilience of the farmers and station owners is amazing and I can't help admiring their tenacity in the face of such devastation. It puts the small things in life into perspective. We took part in a "Farm Aid" Concert" at White Cliffs opal mining town and met some amazing folk.

We then headed for the east coast where it rained every day – shame it couldn't have fallen inland! Now home and in the grip of winter, snuggled up to the fire and catching up some reading. I'm looking forward to catching up with CMT folk at the Seminar in Melbourne on 21st September and I encourage folk to attend if possible – there will be some great speakers and just to be able to interact with fellow "CMTers" is invaluable.
Your Committee is working very hard to create an awareness to the public and allied health professionals of the existence of our organisation in the hope that more folk will benefit from this.

Marilyn Kremmer
Tasmanian State Coordinator and Committee member.
Ph 0409391142 or email mmkremmer1@bigpond.com

SOUTH AUSTRALIA

Sincere apologies to Lisa Moore and our SA members. Your submission for the last newsletter was omitted. Please see below. (Editor)

Greetings from SA. 2019 is off and running in South Australia. Closed Facebook group has grown to 70 members. 55 of these members are from South Australia.

I have had the pleasure to contact and speak with some new persons referred to the support group, and we continue our connection with Muscular Dystrophy Association South Australia with assistance with our advertising. I attended an informative afternoon put on by MDASA with Stretchy Tech – a new innovative company giving tech solutions at home. We will also have them speak at a future SA CMT support meeting later this year. We also will have representative of Brazier Mobility join us at a session, and MDASA to discuss support coordination services they provide for clients on NDIS plans. Notification of these sessions will be posted in the SA Facebook group, and the CMTAA Facebook and Website, to keep everyone informed.

It was wonderful to see the pictures of the Aussie Kids Camp this year, and we are working at having our first South Australian kids attend the camp next year. My son will be attending Camp Capacity, with MDASA here in SA in early April.

Our first coffee and chat gathering was held at the beautiful Lakeside Café in Oakden. The lush garden setting and lake made for a nice relaxing afternoon in the outside seating area. We had many new participants this time, lively discussion and sharing. One of our largest meetings with 10 attendees and a further 4 who sent apologies on the day. Our next meeting will be 8th of June, with location to be finalised in the Adelaide hills.

If any-one is interested in becoming a support contact for their local area in SA, please contact Lisa via the contact details listed on the CMT Australia website – www.cmt.org.au.

NEWS FROM THE REGIONS AND STATES

SOUTH AUSTRALIA (continued)

I attended the inaugural Australian Patient Organisation Network (APON) conference in Sydney on the 2nd and 3rd of May, representing CMT Australia. It was a busy two days, but many interesting topics were discussed, and new contacts made to strengthen CMT Australia and bring awareness of CMT.

August sees me jetting off to NZ for a neuromuscular conference, main theme to enhance self- advocacy for patients, family, carers and professionals in the neuromuscular field. I hope to bring home many useful tips and strategies.

Our second coffee and chat gathering in June was held at Monica's Dine In, Blakes Crossing, in the northern suburbs of Adelaide. James's new boots, with back opening to accommodate his AFO were the hot topic of the day. It was wonderful to see old and new attendees with 6 attending and a further 4 who sent apologies on the day. Our next meeting will be late August with location to be finalised in the Adelaide hills.

July has seen a fundraiser for CMT Australia being held at the Blakeview Primary School. The donations raised on the last day of term 2, for the casual dress day will be donated to CMT Australia.

Many thanks to the school for supporting James and CMT Australia.

Watch this space- plans are being made to schedule some more regional coffee and chat sessions to connect with our members further afield. Details will be available on CMT Australia Website, Facebook and the SA Closed Facebook group when finalised.

If you would like a session in your area, please contact me.

If any-one is interested in becoming a support contact for their local area in SA, please contact Lisa via the contact details listed on the CMT Australia website – www.cmt.org.au.

All the best, Lisa Moore

CANBERRA AND ACT

The May meeting of the Canberra support group welcomed another newcomer to the group. It is always pleasing to have someone new join us, as it shows that the effort put into the CMTAA website is paying off. I seem to receive one or two new contacts by phone between each meeting and the next. A newcomer gives us the opportunity to share our CMT stories – and invariably leads to lots of lively discussion as we attempt to answer their questions.

In early July I attended another meeting with several senior health representatives, following up the previous attempts to get a neuromuscular clinic operating in Canberra. Unfortunately, there has been a recent shake-up in ACT Health, with the resignation of both the Minister and the CEO, amongst others. So this meeting felt a little as if we were back at square one. However, the presence of the newly-appointed director general of Health Services, the head of Rehabilitation Services at UC Hospital and the head of Neurology at Canberra Hospital indicated that the request for a neuromuscular clinic is being seriously considered. I was delighted to have an opportunity to explore the new UC Rehabilitation Hospital. It is very impressive, both in size and fit-out. I'm almost tempted to have a surgery that requires rehab – but perhaps not.

Gabrielle Evans

NEWS FROM THE REGIONS AND STATES

VICTORIA

Hi Victorians,
At the May coffee catch-up at the Abbotsford Convent we were grateful to Patrick, from Nordic Academy, for showing us the benefits of Nordic Walking Poles. The introduction to the poles was a success with some making a purchase on the day and others placing orders on the website www.nordicacademy.com.au . Here is some great feedback from one of our happy CMT warriors:

"Frank now has his 'Poles' -He took to it like a duck to water! He did 20 mins walking which he hasn't walked for a long time – since wearing support orthotics. He was quite comfortable and felt secure and steady – that was a plus! I'm so glad that these were introduced to us – thanks to you! It gives him something to occupy him and is a challenge – all good stuff."

"I am very pleased with the walking poles, I can walk faster when I use the poles, I feel a lot more confident when I am at the park with my dog and I feel that my legs are getting stronger as a result. Thank you so much for the time you invested in opening up this opportunity for the CMT support group, it was very much appreciated."

We have listened to your feedback and have scheduled the next coffee catch-up in a central location that is convenient for public transport users, so hope to see you at Brunetti's in the city, please refer details below.
We are excited to report that we have locked in 7 speakers for the seminar on 21st September. Included in the line up is a guest speaker, the wonderful musician and disability advocate Eliza Hull. For full details and to register please refer to the website www.cmt.org.au

Upcoming Events:
Saturday 3rd August, 10.30am Coffee catch-up at Brunetti Flinders Lane, 250 Flinders Lane, Melbourne
Saturday 21st September, 9.30am – 3.30pm National CMT Awareness Day Seminar at Muscular Dystrophy Australia, 111 Boundary Road, North Melbourne
Saturday 5th October, 10.30am Coffee catch-up, venue yet to be confirmed
Sunday 1st December, 11am Christmas Family Day, venue yet to be confirmed

We would love to see more coffee catch-ups happening around the state but we are relying on you the members to volunteer to host a catch-up in your local area. If you find the city area difficult to get to then let us know where you are located and if you can pick a cafe for members to meet up for a coffee we can then let everyone know of the venue and the time. Feel free to contact me via email: paula_denise@bigpond.com
Warm Regards, Paula Hodgson

(Continued from front page)
The group also enjoyed the success of talented Postdoctoral Fellow Dr Gonzalo Perez-Siles who heads the cell biology program at the Northcott Neuroscience Laboratory. His oral poster abstract presentation describing the use of patient motor neurons to model two different forms of X-linked neuropathy won the Jonathon Pembroke Prize, an award which goes to the best abstract from the Australia-Asia region. Over the last two years, Dr Perez-Siles has been responsible for implementing induced pluripotent stem cell technologies to culture motor neurons directly from stem cells re-programmed from patient skin cells. Through patient donations and grant support received from the CMTAA, Dr Perez-Siles has generated neuronal models for a number of neuropathy genes the laboratory has discovered. "These models represent the cornerstone to developing treatment therapies for these diseases and this award affirms that our research is cutting edge and highly relevant for patient clinical outcomes" said Associate Professor Kennerson.
The success of the Northcott Neuroscience team at the 2019 PNS Meeting highlights the laboratory's important contributions to the international peripheral nerve/CMT research community and endorses the dynamic and progressive research vision Associate Professor Kennerson has nurtured to achieve this level of research excellence.

Invisibility

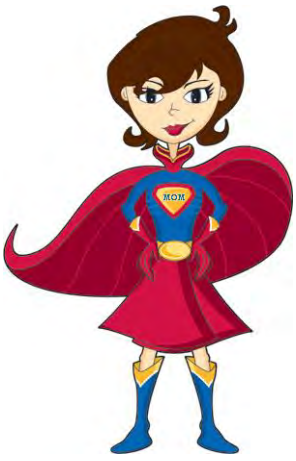
By Shaana Dekker

One of the most difficult things about my CMT is also one of the things I'm grateful for. It's the fact that most people don't know I have it. Although I experience a lot of pain and fatigue from walking, my footdrop doesn't usually become noticeable to other people unless I'm particularly tired. I don't wear my AFOs all the time. People going past me at the shops (a lot of people!) just think I'm walking annoyingly slow on purpose. Or they might wonder whether my death grip on the rail and refusal to move on the travelator is because I'm trying to make some kind of point about patience and being in the moment.

There are a lot of people with CMT who describe their disability as invisible. I guess I would fall into that category although I have always thought of 'invisible disability' as a strange term. It brings to mind some kind of reverse superpower. As if somehow, I might look like your average person, but wait-TA DA-look what I CAN'T do!

Having an 'invisible' disability is a double edged sword in some ways. It's hard to stand out from the crowd and I'm lucky that I can go incognito if I want to. Disability is still something that most people do not really encounter on a day to day basis so their reactions tend to be exaggerated. They can be rude, ignorant and prejudiced. Or they can be over-the-top positive and cloyingly helpful. I don't often meet people who see disability as just 'normal'.

It's probably the overly positive helpfulness that annoys me the most. At least I can argue with the ignorant and rude people. But it's hard to tell someone who is trying to be nice that they're actually making you feel like the star attraction in a pity party. I was once standing at one of those high bar tables and I needed to sit down because of pain. The bar staff went around other tables asking if they could spare a chair for the disabled girl. I then found myself sitting in a low chair at the high table so I had to reach above my head for my drink. Every time the staff came past me, they'd pat me on the back and ask if I needed anything. *Bloody hell.*



If I'm honest, I prefer not to have to deal with all of that and I'm privileged that I have times when I can choose to avoid the abuse, the labels, the stares and the pity. Of course, even though I'm not obvious to other people, I still have a disability. I'm still in pain, working hard to stay upright, watching the ground for things that I could trip on and planning my day around fatigue. I'm still ME.

On the other hand, my invisible superpower also comes with some challenges. Because I don't 'look' like I have a disability, people don't understand the adjustments I need. Like holding on to rails and going slowly down stairs. Like needing to sit down frequently and avoiding queues. Like the unusual way I get up from the floor while holding one of my kids at library story-time (if you're picturing how someone with CMT does this-it's an unglamorous yoga kind of bum-in-the air, elbow-on-the-ground move). I use a mobility scooter for big trips such as the zoo or Ikea, and I get many looks of confusion and sometimes contempt when I hop off the scooter to go and order lunch (LOOK! She's CHEATING!).

I get similar reactions and abuse if I have used an accessible parking space but I don't have my AFOs on (which is ironic since I need those spaces most when I don't have AFOs). I once had a man come over and bang on the hood of my car, accusing me of stealing the mobility parking sticker from someone and 'rorting' the system. I was in tears, my baby was screaming and the day was ruined. And I hadn't even gotten out of the car yet. I just didn't fit the picture of disability to him.

What I've learned most from flying both flags has nothing to do with my CMT. It's about other people. At the risk of descending into clichés, I've learned to be more compassionate and to judge less. Of course, there are still times when I feel like giving someone a piece of my mind but you never know what's happening for other people and what invisible flags they're flying.

Shaana Dekker *is based in Sydney and works as an Advocate at People with Disability Australia, a national disability rights organisation. She is a former Registered Nurse and a recently qualified lawyer. She enjoys helping people navigate government beurocracy and finds ticking boxes and filling out endless streams of paperwork peculiarly satisfying. In her spare time she enjoys rolling around the floor with her three children, savouring a wine with her husband, and trying to find nice shoes that fit her AFOs (mission impossible!).*

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

By John Arbouw

The news that the Federal government has sanctioned a Royal Commission into Disability Abuse will be welcomed by all those who have suffered.

Disability abuse is the end result of ignorance concerning both physical and mental disability. It is this ignorance that must be confronted through new public awareness programs and in educating government bureaucrats.

There has, for too long, been a mindset on every level of society and government that people with disabilities are just an unfortunate minority that can be catered for with a few funds here and there.

It isn't until a family member is injured, in say a sporting accident that the family becomes aware on a personal level that getting on and off trains, buses, or going up railways stairs because there is no lift is a daily problem faced by the disability community.

It isn't only the disabled that face these daily hazards. Everyone who has ever taken public transport has seen mothers struggling with prams and old people's long journey of one stairway step at a time.

Disability abuse? Mother abuse? Elder abuse?

The reality is that failure to understand these issues is one of ignorance that can be resolved through better education.

This is especially required within government departments. In Qld, the government is buying 75 new trains but the project is delayed and has gone over budget because the bureaucrats within the government came to realise too late that there was not sufficient disability access.

There are a myriad of similar examples throughout the country where these types of things have occurred. If the needs of the community as whole is taken into account from the initial planning process these things can be avoided and ultimately save money.

But disability abuse has a darker side than merely ignorance. In the same way that the MeToo movement has highlighted powerful men in Hollywood and the Church using their position to abuse vulnerable young people, disability abuse of any kind has the same dynamics.

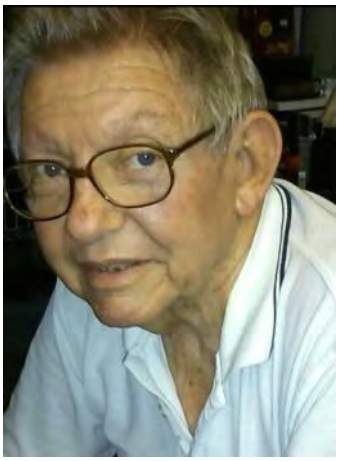
It is the power equation at play.

There is no doubt that some of the carers that have been put in positions of relative power over disabled people in a home or institutional facility have abused that power sometimes resulting in tragic results.

Fixing this is no easy task. Hopefully, the Royal Commission will make some meaningful recommendations on these issues.

John Arbouw *is 74 years old and is a journalist, author, corporate adviser and company director. He has worked in Canada, Holland, Singapore, New Zealand and Australia. He has written for newspapers and magazines and is currently the Australian Editor of Project Finance International which is an online publication based in London and owned by Thomson Reuters. He says his biggest success was marrying his wife Susan, being the father of an extremely talented and kind daughter and the Opa (grandfather) to three wonderful grandchildren.*

OBITUARY: KELVIN GRAEME (KEL) ABRAHAM



The death of Kelvin came as a shock and a sad blow. He had been hospitalized on account of complications stemming from Gout and a staph infection, Septicaemia, and passed away due to renal failure on the 4th June. I attended the funeral on the 14th June at Stapylton, south of Brisbane, to pay my respects to a man I admired, respected, and called a good friend, although in recent years we had not been so much in touch. I first met Kel after I had been diagnosed with CMT in my early 50's. It was a time when David Fennell, who was a driving force behind the setting up of a National office in Sydney, was visiting Brisbane with a view to having a support group there.

I was invited onto a committee for this purpose that comprised of Kel and his wife Bev, daughter Vicki, Alan Rolandsen and wife Rosie, Margot Fennell (David Fennell's sister) and myself. This was back in 1994 with a committee, energetic and full of ideas. Picnics in the park were organised. I recall at least three seminars over a few years were arranged; the first at the Leukaemia Foundation in 1995. Bev and Vicky were very professional in the planning and organising the catering all under Kel's guidance. I would say they were up to the standard of the Awareness Day, one I attended in 2016 at Kedron-Wavell services Club in Brisbane and Prof. Garth Nicholson was also the keynote speaker at each. We posted out a regular newsletter for a while that mainly Rosie Rolandsen produced.

Around this time there was talk amongst those running the local associations, in support of other neurological diseases such as MS, MN, Parkinsons and others, regarding the feasibility of having an umbrella group operating out of a single building in Brisbane with all the professionals under the one roof; a big vision indeed. Over a few months Kel and myself spent quite a bit of our time being invited and attending the different offices of these groups in Brisbane, having group meetings. I can readily recall that Kel contributed effectively in discussions and his comments valued. In the end the vision was not pursued but important contacts were made. On our visits Kel and I had a great time while I did the driving, and he was telling his stories and jokes. I know he enjoyed himself as I did.

Going great guns, the committee obtained a grant for office equipment and Logan City provided an office for CMT in one of their buildings. It didn't work out the way we had imagined as enquiries or visits rarely came through the office yet it still had to be manned. Kel who, anyway, continued to take calls at home often at all hours so we closed the office.

As a lay- person I don't think anyone knew more about CMT than him and being the local man he was the one we directed people and members to. I don't think there was anyone who was not helped by Kel and received the information they were looking for. I put it down to volunteer fatigue but eventually the committee dissolved and to her great credit Margaret Burke took over as Queensland Coordinator and filled the void admirably. Whilst his concern for CMT people and their families continued he loved helping anyone and anyway he could. I know that he was constantly on the lookout for people on the street with the disease even occasionally approaching them at shopping centres and saying that he had noted how they were walking, and asking did they have CMT or were aware of it, much to Bev's apparent embarrassment at times, but it always ended well with many thanking him for his advice. I picked up on this habit and to this day can't help myself approach anyone I spot with the symptoms. When my wife is with me she slips into the background.

About five years ago he volunteered at the Princess Alexander Hospital in Brisbane to help them with their training of new doctors so they could learn to diagnose the condition he had. The majority of them got it wrong. It was no surprise to him, as it is to us, that many trained doctors haven't heard of CMT or aren't able to diagnose it correctly. He joked that even doctors at the QEII, his last hospital, thought CMT was a heart disease! His father was a policeman and Kel kept up a connection with the Queensland Police Force and was a volunteer in "Policing (VIP)" out of the Logan Central police station until 2014. Also he was a Justice of the Police (JP) for fifty years. *(Please turn over)*

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At the funeral Bev kindly allowed me to say a few words as Kelvin junior, Vicki and a grandson talked mostly from the family and friends perspective. She was happy that I could say a few words about his contribution to CMT Association. I told the assembled family and friends that I was not there in any official capacity, and since I had not prepared, I only touched on some of the aspects I have mentioned, although sufficiently I hope, to have given him the credit he was due.

Not all current Queensland members would have been aware of Kel and his contribution but on behalf of our members I salute the life of a lovely man who was well loved and who never let the limitations of his physical condition get the better of him. To his family, and particularly his widow Bev, our prayers and thoughts are with you all as you deal with this huge loss and the hole in your lives his death has bought.

John Gold

A FEW WORDS FROM THE NATIONAL OFFICE

I think that I am the only member still on the National Committee who worked with Kelvin when he was the Queensland State Coordinator for CMTAA. Like John, I have very fond memories of Kel (as he was usually called). He was a wonderful person, very dedicated to promoting awareness of CMT in the Qld community and medical professionals and with his family and other members of the Queensland Committee worked extremely hard in assisting people and their families with their management and treatment of CMT.

The President and National Committee extend their sincere condolences to Kel's wife, Bev & their family.

Anycie Berkmann, Secretary of CMT Australia

CMT Aussie Kids
www.cmt.org.au

Did you know that CMT Australia through the CMT Aussie Kids program has been supporting Australian youth with CMT since 2012?

* Over 160 kids have attended the annual camps over the past 7 years.

* The program has touched the lives of over 150 families, providing support, guidance, information and encouragement.

* CMT Aussie Kids and their families have raised well in excess of $25,000 towards research into CMT in addition to funding the CMT Aussie Kids program.

* CMT Aussie Kids have experienced rock climbing, sailing, canoeing, giant swinging, flying foxing, and archery-ing (!)

* The program has engaged with community groups at the Concord Hospital ANZAC Institute and Sailors With Disabilities, (to name a few) to further develop knowledge, skills, understanding and resilience.

* The CMT Aussie Kids Mentor Program has nurtured young adults in leadership roles to maintain and ensure the future development of the CMT Aussie Kids Program.

* We've hosted a group of 10 kids and young adults from the UK at their camp in 2016, and then had a reciprocal visit to the UK in 2018, fundraising over $6000 each to get there.

* Youth members have travelled to Sydney, Brisbane, Hobart & Melbourne to present at the CMT Australia National Seminars

* Our social media presence provides a safe network for youth to discuss their CMT, share experiences and support each other year round, in fact, that there are over 235 members in our closed Facebook group.

* Our youth members come from across Australia and New Zealand including major cities and rural and remote locations including Townsville, Perth, Hobart, Canberra, Darwin, Sydney and Auckland.

* We do this without any government support or funding.

If you're a kid or young adult with CMT living in Australia or New Zealand, or a parent of one, why not get involved? You never know where it might take you. Contact Peter and Jillian on 0428 221 264 or email cmtaussiekids@gmail.com to see what the CMT Aussie Kids Program can offer you.

CMTAA
Charcot-Marie-Tooth Association Australia Inc.

PRESENTS
The 2019 National CMTAA Seminar

Saturday, 21st September 2019
9.30am to 3.30pm.

Muscular Dystrophy Australia – 111 Boundary Road, North Melbourne, Victoria
MDA is about 10 minutes from the CBD. Disabled parking and regular parking available in the street. Train and tram access is within 200 metres of MDA.
No steps into the building. Lift available to the first floor conference room.
Registration and Morning Tea from 9:30am. Speakers start 10.15am.

Speakers include:

Professor Garth Nicholson, Neurogeneticist – Update on CMT research
Professor Joshua Burns, Professor of Paediatric Neuromuscular Rehabilitation - Management of CMT
Dr Rachel Kennedy, Physiotherapist, Neuromuscular Research at Royal Children's Hospital
CMT Aussie Kids, Peter and Jillian Critchley
Brotherhood of St Laurence, Supporting people with disability to navigate the National Disability Insurance Scheme (NDIS)
Julieta Mateo, Awareness Through Movement Practitioner, Feldenkrais Method - improving human life through exploring better movement.
Guest Speaker - Eliza Hull, ABC Producer, Musician and Disability Advocate

Displays:

Neuro Muscular Orthotics of Melbourne - Customised Orthotics
Orthopaedic Appliances - Off the shelf Orthotics by OAPL
Extra Depth Footwear - Therapeutic & Comfort Footwear

Cost- Non members - $25 , children under 18- $15, Members - $20
Family $35 where one is a member (eg partner, carer or children)
This includes morning tea and lunch.

Please register **your attendance and make payment through the Seminar RSVP link at the end of the National Melbourne Seminar article on the CMTAA website (cmt.org.au) or by emailing cmtaa2@cmt.org.au or phoning the National Office on 02 9767 5105 by *September 14th*.**
If you have any queries, please ring Paula (Melbourne) on 0419351765 or email paula_denise@bigpond.com
Registering is essential for catering purposes
Please notify us if you have any medical dietary requirements.

A Certificate of Attendance is available

NEWS FROM CMT AUSTRALIA

GiveNow Fundraising Page

CMT Australia are excited to announce we have set up a new fundraising page for people taking part in Fun Runs. GiveNow is Australia's first and best giving platform, offering opportunities for people to donate to a particular cause safely and efficiently, without extreme overheads for us. We have previously used a Give Now page to raise funds for the CMT Aussie Kids trip to the UK Kids camp last year. We have had some interest from members taking part in the Sydney City 2 Surf fun run in August and this GiveNow page can be used to fundraise for just these types of events. All donations go directly to research into CMT. To donate or support a runner go to https://www.givenow.com.au and search Fun Runs For CMT. Please contact our office if you wish to set up an individual fundraising page and we'll guide you through the steps.

National Disability Strategy

The National Disability Strategy 2010-2020 is about creating a more inclusive society that enables Australians with disability to fulfil their potential as equal citizens. It is also the main way Australia implements the United Nations Convention on the Rights of Persons with Disabilities in Australia, making sure people with disability can participate in all areas of Australian life. The Strategy is a shared commitment by all governments to work together to improve the lives of Australians with disability by guiding governments and other organisations to build the wellbeing of people with disability and their carers. From April, the Australian community is invited to take part in national consultation to shape the future of disability policy for 2020 and beyond. Consultation will ensure people with disability are at the centre of the design of the new strategy and have a leading role in modernising policies and programs affecting their lives . Go to https://engage.dss.gov.au for more info

Would you like to join a CMT Support Group?

CMT Australia is continuing to organise local CMT Support Groups for our members and their families. To do this we need interest from our members to participate in meetings or 'coffee mornings' and also a person willing to be the coordinator for their area.

These meetings or get togethers can be an opportunity for members and their families to discuss their problems, swap information and support each other; just having someone to talk to who has the same or similar problems as yourself could help you and your family in many ways.

CMTAA wants to address this situation by encouraging members of our CMT "Family" to participate in a support group and this can happen in both rural communities as well as town and city locations.

If you are interested in joining, please contact us at the National Office. Your name and phone contact number only will be made available to other CMT members also residing in your area who are also willing to participate.

If you are interested in being the contact person for your group let us know!

Mrs. Anycie Berkmann, Secretary, CMT Australia

CMT Australia AGM

All members are welcome to attend the Annual General Meeting of CMT Australia at the ANZAC Research Institute Conference Rooms, Concord Hospital at 1pm on Saturday, 19th October 2019. Please RSVP to the National Office on 02 9767 5105 or email cmtaa2@cmt.org.au

A Positive Encounter With a Stranger Who Has CMT...

I was leaving a café recently when I noticed a man who had the characteristic "CMT gait". Curiosity emboldened me to ask the question:

"Excuse me, I don't mean to intrude, but do you have a neurological condition in your legs"?

His response was "yes" and he added that it was a condition called CMT. I responded that I am also a member of the "CMT family". He then invited me to sit down for a chat. He did not know about CMT Australia and with the exception of drop foot supports on both of his shoes he didn't have any CMT management strategies. He shared when he was diagnosed and that his brother had also been diagnosed with CMT. He also told me how he and his wife had made accommodation choices that assisted in prolonging mobility without undue risk. I mentioned there are numerous management strategies and aids that can enhance daily quality of life. These were discussed with him and I explained what I was currently using and how they were very beneficial and worked for me. Aids such as under-toe supports, special orthotics, shoes for maximum support and stability and regular personalised exercises from an Exercise Physiologist. I gave him the CMT Australia website details and also the name of a podiatrist who had a practical understanding of CMT and whom I had found very helpful. He had a positive attitude and it was a mutually encouraging experience.

Darryl Beitsch

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Vacant

Adelaide South
Vacant

NORTHERN TERRITORY

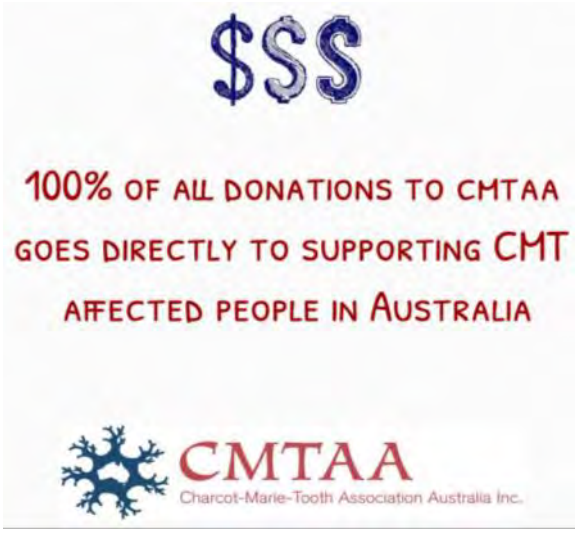
Darwin
Mrs. Kaye Bartlett (See above)

NEW ZEALAND

Vacant

THANK YOU for donations from 1st April 2019—

Your donation is what enables your CMT Australia to reach it's goals: Fund Research, Disseminate Information and Support Projects like the CMT Aussie Kids Program.



$2000 and over

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Mrs. Kitty Farrow	Miss Margaret Lampe	Ms Takako Matoba

DVDs NOW AVAILABLE

September 2018 Hobart CMT Seminar DVD is now available to purchase. For those who are unable to attend, each year we video the Speakers who present their Topics on the Day and make the DVD available for them to view on their home TV's or computers. A price of $10 applies and this includes postage and packaging. Purchase can be made by ordering through our website www.cmt.org.au or by phoning (02) 0767 5105 or email: cmtaa2@cmt.org.au

To order online just click on the link 'Support Us' and then click on 'DVD sales' and complete your details and payment options. Your copy will be promptly posted out to you.

2018 SPEAKERS AND THEIR TOPICS INCLUDE:

Professor Garth Nicholson, Neurogeneticist, Concord Hospital, Concord, NSW: New Developments in CMT Research.

Professor Joshua Burns, Professor of Paediatric Neuromuscular Rehabilitation, University of Sydney and Westmead Children's Hospital, NSW: Developments in the management of CMT.

Professor Greg Peterson, Professor of Pharmacy, University of Tasmania: Drug Therapy for Neuropathic Pain.

Mr. Darren Pereira: Principal Orthotist, Neuromuscular Orthotics, Melbourne, Victoria: The use of Orthotics in managing CMT.

Mr. Hamish Anderson, Physiotherapist, Hobart, Tasmania: Balance, Exercise and Fatigue.

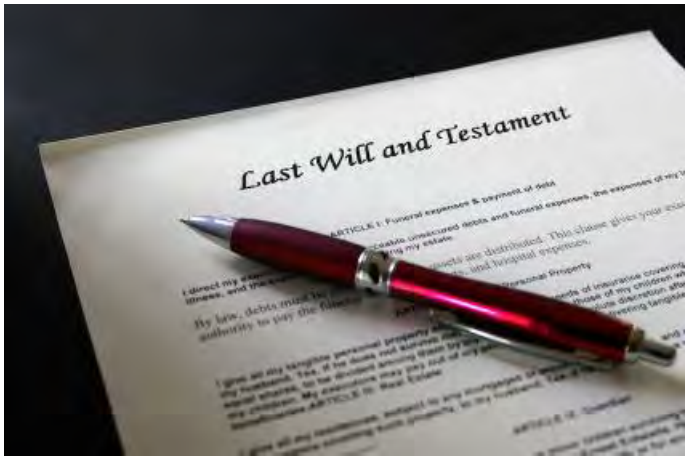
CMT Aussie Kids presentation by: Peter, Jillian and Eleanor Critchley and Sarah McIntyre.

Question and Answer Session: All Speakers participating in answering attendees questions on CMT.

PREVIOUS SEMINAR DVDs from 2011—2017 are also available by contacting the CMTAA Office.
Also available Grace Warren's Hand Exercises DVD at the special price of $5.

LEAVING A BEQUEST IN YOUR WILL

Since our early beginnings more than 30 years ago CMT Australia have relied on the work of our volunteers to support and move the organisation forward to where we are today, along with the donations from members. CMT Australia receives no government funding. You can decide to leave a gift to CMT Australia in your will and help fund the many potentially life changing activities undertaken by us.



Leaving a bequest in your Will towards research, youth activities or administration will support so many others with CMT in the future. Your bequest is more than a gift - it is a lifetime of hope!

Please contact our CMT Australia National Office on 02 9767 5105 or cmtaa2@cmt.org.au to find out how you can leave a bequest in your will.

The **CMT CoMmuniTy newsletter** is produced approximately every four months for the information of CMT AUSTRALIA members. The Editor is Jillian Critchley.

All contributions, letters, and enquiries should be directed to the Editor, CMT CoMmuniTy newsletter, 15 Naranga Avenue, Engadine 2233 N.S.W. or email: cmtaa2@cmt.org.au

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Donate to CMT AUSTRALIA

Please follow the steps below to donate to the CMT AUSTRALIA:

Go to https://www.cmt.org.au/control/donate

OR

Electronic Funds Transfer payment : Our bank details are: BSB: 032-069 Account number: 158486

Please indicate the code/s below that your payment has been allocated to, along with your surname for the transaction information.

R—Donation to research
A– Donation to administration
Y—Donation to CMT Aussie Kids Youth Activities

Please email us at cmtaa2@cmt.org.au letting us know of your donation.

Your donation is what enables your CMT AUSTRALIA to reach it's goals: Fund Research, Disseminate Information and Support Projects like the CMT Aussie Kids Program.

ARTICLES AND IDEAS

Your letters and articles are very welcome. This is your newsletter. Let me know what you want. Ideas, letters, articles, photos, anecdotes...anything is welcome that is CMT related.

Deadline for next newsletter: 31st October 2019

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

15 Naranga Avenue, Engadine 2233 N.S.W.

Email: cmtaa2@cmt.org.au

Charcot-Marie-Tooth Association of Australia Inc.

The Association is incorporated in NSW and a registered charity (No.CC28099)

ARB No. 076 189 912

ABN No. 63076 189 912

Donations $2.00 and over are tax deductible (DRG No. 018352).

PLEASE NOTE: WHEN PAYING YOUR MEMBERSHIP RENEWALS BY ELECTRONIC FUNDS TRANSFER (EFT) REMEMBER TO MAIL YOUR MEMBERSHIP RENEWAL FORM TO CMT AUSTRALIA SO WE CAN ENSURE YOUR DETAILS ARE CORRECT AND UP TO DATE AND WE KNOW FROM WHOM THE PAYMENT HAS COME. IT WILL ALSO HELP US TO ACCURATELY ALLOCATE DONATIONS AND ANY EXTRA PAYMENTS MADE. IF YOU INCLUDE YOUR MEMBERSHIP NUMBER IN THE EFT TRANSFER DETAILS WE WILL FIND IT EASIER TO RECORD YOUR PAYMENT. IF PAYING BY CHEQUE, PLEASE ENSURE YOUR NAME & MEMBERSHIP NUMBER IS WRITTEN ON THE BACK OF THE CHEQUE .

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TOTAL **$ _____**

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OR By Cheque made payable to :Charcot-Marie-Tooth Association of Australia Inc. and post to: CMTAA Bldg 22, Concord Hospital, Concord NSW 2139

THE BACK PAGE

Some words from the wise

"Let me embrace thee, sour adversity, for wise men say it is the wisest course."

— William Shakespeare

"Life is thickly sown with thorns, and I know no other remedy than to pass quickly through them. The longer we dwell on our misfortunes, the greater is their power to harm us."

– Voltaire

"Success is not final, failure is not fatal: it is the courage to continue that counts."

– Winston Churchill

CMTAA
Charcot-Marie-Tooth Association Australia Inc.

Foot power is proud to be a

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