

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 76 Autumn 2014



CMTAA

Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

EVEREST TREK TO RAISE FUNDS FOR CMTAA

Kevin Howlett owns and runs a publishing company *Busybird Publishing* in Victoria. He will be trekking up to the Mount Everest Base Camp, taking photographs for a glorious full colour coffee table book entitled *Walk With Me*. 'That's nice', I hear you say. 'but what does that have to do with CMT?'

Kevin and his wife Blaise's son Dylan has Charcot Marie Tooth. A promising footballer in his youth, Dylan has had to have both feet reconstructed, and now has impediments on distances he can walk and what he can do. Kevin plans to trek to Mt Everest Basecamp to increase awareness of CMT.



Kevin explains: 'This all came about from a challenge a friend and me had to do something adventurous before we are 50...so we decided to travel to Nepal and trek to Mt Everest Basecamp. I also wanted the trek to be for something...a reason, motivation and I can't think of a closer thing to our family than CMT. My 20 year old son was diagnosed with it at about the age of 13. A very keen football player he had to give all that up and has gone through a year of 2 feet reconstructions and now lives a content life but we all know the CMT will fight against the construction and one day surface again. We try to follow the research into CMT and know it is not widely known or funded and that's where I would like to help'.

Proceeds from *Walk With Me* will go to CMTAA to help find a cure and raise awareness.

Kev's expedition to Everest is fully self-funded. He has twenty-five years experience as a photographer, and he and Blaise both have over a decade of experience in design. They are committed to the labour of the book's production. This is not a glamorous endeavour aimed at profits, but improving quality of life for people with CMT, and raising public awareness of the disease. Kevin expects the book to be published later in the year, with proceeds going to the CMTAA.

If you would like more information on the trek or how you can support Kevin in his mission please visit http://www.busybird.com.au/?page_id=2967

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

PRESIDENTS REPORT with Darryl Beitsch



My Fellow “CMT Family” Members,

Thank you to those members who have offered to volunteer their time as Support Group Coordinators. It is very reassuring to know that we’re not alone and we all have something positive to contribute when we attend these groups regarding how we manage our CMT. Your CMTAA Secretary, Anycie Berkmann has been doing an excellent job in promoting the advantages of being a member of a Support Group.

We have had an encouraging response from our members to my letter outlining how to login to our new website to view newsletters and Awareness Day Seminars. For the benefit of our members, there will be more seminar videos appearing on our website in the near future. As a part of the upgrade to our National Office procedures, those who have logged into the website will be receiving an email 4 weeks prior to their membership renewal date. We are also planning to have the capability to send renewal and donation receipts by email which will significantly improve efficiency for our office volunteers.

For your convenience, through our website www.cmt.org.au, we now have an online Membership Renewal facility with 3 payment options. If you choose the Credit Card/PayPal option for membership renewal and would like to make an additional donation, please click on the separate “Donate Here” button located on the Home Page for your donation payment.

A big percentage of the enquiries we receive focus on who are the medical and allied health professionals familiar with CMT located in a specific area. The good news is that the CMTAA is in the final stages of completing a list of these medical and allied health professionals that will go a long way to answering these enquiries.

Some more good news, we are currently preparing for the CMT Youth Weekend - Friday August 29 to Sunday August 31 and the Sydney Awareness Weekend - Saturday afternoon October 11 and Sunday October 12. We are optimistic that there will be CMT Awareness Day activities in other areas in Australia.

Take care and keep moving.

Darryl Beitsch

President

NEWS FROM THE STATES

TASMANIA

News from Tassie -

It was great to welcome four new members to our Christmas Get-together – what a great bunch of folk – all sooo positive. This was the first time we had got together since our Awareness Day in July which our four new members attended.

This just shows that the more publicity we get we can reach out to all those folk with CMT. Networking!! Following our afternoon I received this email—“**** came home so excited, he knew that other people with CMT existed but finally got to speak to them and he doesn’t feel so isolated.” This is what support groups are all about.

Congratulations to the CMT committee for the new website – fantastic!

Best wishes go to all members and may 2014 be a good year for you all.

Kind regards

Marilyn Kremmer

Tasmanian Support Group

NEWS FROM THE STATES

GOLD COAST

Hi everyone! Judy here with greetings from the Gold Coast. Hope you are all keeping well and coping with the heat alright. We had our meeting the other day, and I'm pleased to say that there were a couple of new faces. Please note that there will be a meeting on Monday the 28th of April at CSI Southport, Scarborough St, Southport starting at 10.30 am. A lot of interest is being shown in the new Web site, and a lot of talk about different orthotics, so I am hoping to line up a couple of guest speakers. In keeping with the theme of positive things that can happen even with MT. This is one of my favourite stories from my childhood. Being one of five children and having mobility issues since birth, I was never able to run around like all the other kids in the neighbourhood did, but I did build the best billycart and won most of the races I went in, which showed me that everyone has something that they are good at, which enables them to have fun and feel good about themselves. Until next time, take care and remember to keep smiling. Judy.

NEWCASTLE

I have organised a meeting on Saturday, the 12th April for our Newcastle members and anyone else who would like to attend. It will be held at Valentine Pool in their function room. This is a good opportunity to meet with others who have CMT and how we cope on a daily basis. Hoping to see some new faces at the meeting.

If you would like to know more I can be contacted on 0412 891 647.

Gabby Cosgrove, Newcastle Co-ordinator

SOUTH AUSTRALIA

Hi Antonia here, greetings from SA. I trust everyone had a very Merry Xmas and a great start to the New Year. After a restful break, I am eager to hear and meet many more SA members including any prospective members! I sincerely thank the enthusiastic Isabella, Lisa, and her beautiful son James for attending the December 2013 gathering. It was a small but fruitful gathering. Thank you to those that forwarded your apologies. Our informal gathering commenced productive discussions for what we would like to happen for SA in 2014. In March this year another get together welcomed another enthusiastic member Francesca Herdahl-Thorsing to the team. The session was very productive. Our discussions focused upon ways to provide benefits to SA members. It was identified, that we needed an increased SA awareness, broader SA contact base and increased SA communications. Following the gatherings, the following steps have been taken. Increased SA Awareness. Thanks to Lisa for all her efforts in creating the SA Facebook site CMT – SA Region. Through Facebook, we have connected with NOVITA, Women's and Children's are Hospital, the Northern Communities Bulletin Boards and Gawler Happenings and plan to extend this presence. Increased Communications. We anticipate using our national Website and Facebook more effectively, the CMTAA newsletter, ordinary correspondence, and DL flyers in electronic and hard copy. Increased SA Contacts. Thanks to members Francesca (Southern districts) and Lisa (Northern districts) who have kindly offered their contact details below. I will continue to cover the Western districts. This means that we will have contacts in all but the Eastern districts. Any volunteers? Our working team is now four members strong. We are looking for more volunteers to build this dynamic team and invite our members to contact us. Remember, our aims are to identify ways in which the SA region can provide local support making life a little easier for those living or caring for sufferers of CMT.

We look forward to seeing members join us at the planned sessions on - 22 June, 21 September* and 14 December 2014. * SA awareness day

Time: 2-4pm Location: State Library of SA North Terrace front foyer entrance area.

Kind regards from the team SA. Antonia 0416051438 Lisa Moore: mobile: 0459 084 437, Isabella Frisan and Francesca Herdahl-Thorsing mobile 0420 870 263

WORKEY

A recent email to the CMTAA office alerted us to a new device that has been invented by one of our members sons. Alan Rolandsen writes:

'I have always experienced some difficulty in opening heavily sprung locked doors found in commercial or industrial buildings. After complaining about this to my son, he set himself the task of designing and producing a device to make key turning easier. The result is the 'Workey' - a light-weight key turning device which can be used to overcome the resistance of these heavily sprung door locks. The Workey slips easily onto a key ring or into a handbag.

A door key is inserted through the aperture in the centre of the Workey (with enough friction being applied to the key to hold it in place). The key is then placed in the lock and the additional leverage of the Workey enables the unlocking to occur.'

Alan would be happy to be contacted either by email: a_rolandsen@hotmail.com or mobile 0421 659 048. You might also like to check out the website <http://myworkey.com/>



Foot and Ankle Strength Training for Charcot-Marie-Tooth Disease (CMT)

A major problem for children with CMT is foot weakness. Currently there are no effective treatments for this problem. Strength training might be beneficial, but is untested in CMT.

We are performing a study at The Children's Hospital at Westmead (Sydney) looking at the effect of foot and ankle strength training in children with CMT aged 6 - 17 years.

If you have a child with CMT or know of any children with CMT who might be interested in this clinical trial, please contact the investigators:

Associate Professor Joshua Burns and Dr Amy Sman
Institute for Neuromuscular Research,
The Children's Hospital at Westmead, Sydney
Phone: (02) 9845 3004 or Email:
amy.sman@health.nsw.gov.au



KIDS WEEKEND ORGANISERS MEET UK COUNTERPART



The Critchley family had planned their UK trip for a long time and were keen to meet up with the organiser of the UK Youth Weekend camps. Peter and Jillian Critchley established the Aussie Kids Weekend after discussions with Karin Rodgers, the organiser of the UK camps. Karin's infectious enthusiasm for these camps and her shared philosophy behind the weekends helped motivate the Critchleys to establish the Aussie Kids camps nearly 3 years ago. From early emails and Skype calls through to the fruition of the kids camps the friendship between the Critchleys and Karin has always been strong. Karin (who has CMT) and her

husband Kevin met with Peter, Jillian and their daughters Matilda, aged 15 years and Eleanor, aged 11 years (both with CMT) during a recent family holiday to the UK. They spent a day touring the Peak District near Manchester in northern England. Karin and Kevin's generous spirit and fun attitude to life made it an amazing day, filled with chat and laughter. Stories and ideas were shared, and more than a few tears were shed when they had to say goodbye. However CMT has brought 2 families together from across the globe, and strengthened the bond between all kids with CMT. Above From left: Jillian, Eleanor, Peter, Karin and Matilda at the Heights of Abraham at Matlock, UK

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CMT AUSSIE KIDS ARE AWESOME

Encouraged by staff at Sydney Children's Hospital to take up a non-weight bearing sport I began riding. After taking my brothers invite to a Paralympic Talent Search ID Day, I discovered para-equestrian and was later classified as a Grade 3 para- equestrian rider. The para- equestrian grades range from riders severally impaired to riders moderately impaired in the following order; 1a, 1b, 2, 3, 4.

Riding is, and has been the physically taxing and mentally draining activity I've ever tried. Though, it is also what motivates me to become somebody that I can be proud of.



Everything takes me longer to master than the other kids; I struggle to use my legs and hands to signal the horse and to fight off my fatigue. I rely heavily on a combination of my body weight and core muscles, voice aids and artificial aids. In my early riding days I constantly fell off; my record stands at 4 falls in 60 minutes but if anything, this has only made me more determined to improve.

Affectionately known as 'weakey,' amongst my horsey friends, I have earned my place as a rising star at the stables with the help of my horse Cruise.

In 2013 we competed in the NSW and National Para Dressage Championships and in the process qualified for an international event. At States and Nationals we rode 3 tests; an Individual championship, a Team Test and a Freestyle to music. These tests are the FEI Paralympic tests. At 16 and 17, I was the youngest competitor at both events by 4-5 years and the most novice rider with only 3 ½ years riding experience. I was competing amongst Australia's Elite horse & rider combinations and having a blast!



My determination to be the best version of myself, kindled with an unbridled passion for riding has lead to these achievements. I encourage all CMT kids to find a sport which they love and have a go at it. Getting your endorphins pumping is a sure way to make you smile and feel great!

Jemima, CMT Aussie Kid

I'm a member of the Sutherland Shire Ranger Guides, the senior section of the Girl Guides and recently we went on a weekend to Jindabyne, near the snowfields of NSW. On this weekend we did some activities including geocaching (which is like electronic orienteering) and of course, shopping. However



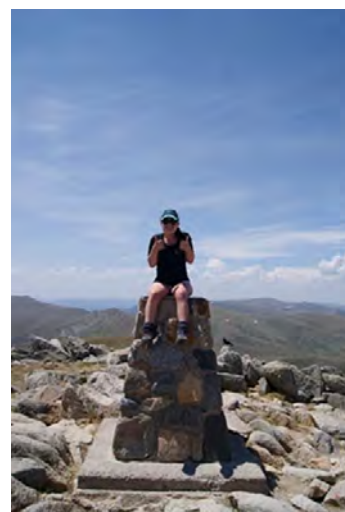
the highlight of the weekend was one of the biggest challenges of my life. Climbing Mt Kosciuszko. I knew this would be a challenge because of my CMT but with my Ranger Guide friends around me for support I was determined to get to the summit. Our plan was to reach the summit at sunset and watch the sun go down but after investigating in the morning that bad weather was forecast we decided to go up around lunch time.

We set off taking a ride up the chairlifts from Thredbo, and started our 7km ascent to the top. The weather was sunny and warm, but as the clouds loomed there was always the risk that the predicted change would come early, and even in summer there is a risk of adverse weather including snow. Being able to sustain the constant walking was a big challenge. However I had the best motivation in the world to make it to the top—my Dad who also has CMT has never achieved this feat.

At approximately 2:30pm that afternoon we linked our arms and walked to the cairn that marked the summit. I felt proud and accomplished. We took photos to mark the occasion. We danced, we sang, we celebrated our achievement. Then we started the long trek back to the chairlift making sure we made it back in time for the last run. By a stroke of luck as we arrived to take the chairlift back down to Thredbo the heavens opened.

CMT won't stop me!

Matilda Critchley, CMT Aussie Kid



IT'S ON AGAIN! CMT YOUTH WEEKEND 2014

The Charcot Marie Tooth Association of Australia will be hosting another fun packed weekend in a supportive and caring environment for all 'kids' with CMT. Don't miss this opportunity to share and connect with other youth with CMT.

WHEN: Friday 29th –Sunday 31st August 2014.

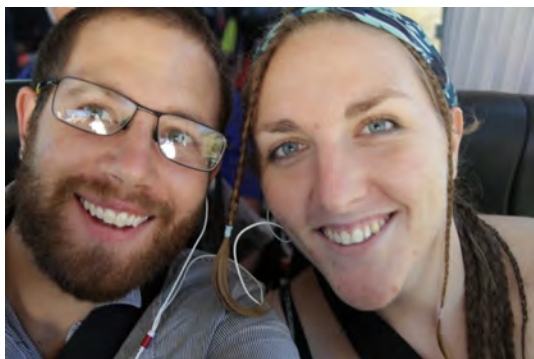
WHERE: Berry Sport & Recreation Centre NSW (just two hours south of Sydney).

AGE: 10 to 17 years with 18+ welcome to be mentors.

COST: TBC including all meals from Friday dinner to Sunday lunch, passive and adventurous activities and accommodation.

REGISTRATION: For more information regarding registration, sponsorship for Youth Weekend Fund and donations please contact: Jillian via email cmtaussiekids@gmail.com or call mobile: 0428 221 264

I went to Vietnam (just don't tell Mum)



I'd been in Vietnam for less than two hours and already I had lost my luggage, got it on the next flight, found a taxi driver who knew where to go, and ended up on the back of a motor scooter going 60 km/h down a main road with 2 backpacks on and no helmet. The strange thing is that none of this was scary.

Vietnam is sensory overload with national borders and a government. The sights, the people, and scooters everywhere remind you that you are not in Oz.

The next day a spent cartridge from the AK-47 Meaghan was shooting bounced off my camera, and two minutes after that we were watching a lady making rice paper. On the bus trip back from the Cu Chi tunnels, the home of the rice paper lady and the Russian firearm, we pointed out to each other that we had now been in Vietnam for 24 hours.

So far we had seen plenty of Vietnamese family's all-on-one scooter and thought "how hard can it be?" So myself, Meaghan, and our man-on-the-ground Dhieu, all jumped on Dhieu's scooter and headed out for dinner. This went fine until we tried to order a vegetarian dish by using our (mistake here) Vietnamese. What we got was four shellfish dishes. It's advisable not to eat shellfish in a country as polluted as Vietnam, so our dinner was of a more liquid variety.

Bus lotto is the game of picking a direction and catching a bus and seeing where you end up. We ended up in Vung Tau. We arrived at Vung Tau to find a square like every other part of a Vietnamese city. This did not look promising. Sometimes in bus lotto you lose. We started walking towards the beach and as the local mountain came into view we saw it was topped with a Rio-like statue of Jesus, we later found out that it was also home to two 15-inch gun turrets. That night we enjoyed a game of pool in a local pub called the Ned Kelly, and realised we had found a real pearl of a place.

You can't go to Vietnam and not hire a motorbike, so we did; from a couple of Australian bikies who now live in Vung Tau. This presented the first challenge for me. The controls for the indicator on a motorbike are little switches that require you to use your thumb. My thumbs are not the most useful of digits owing to my CMT. Happily I was in Vietnam, and no one really minds if you don't indicate... so I didn't.

We caught a hydrofoil ferry back to Saigon. A few days later one of these caught fire and 90 people had to jump into the Saigon River.

The following 30 hours were quite unpleasant due, no doubt, to something I ate in Vung Tau. But after some rest and reading we headed to the train station and off to Na Trang. At 10 o'clock in the morning we were woken up by the attendant to let us know we were near our station, so we walked to the beach side park to watch the sun rise over the South China Sea and sleep one at a time in the hammock. After a night in a fantastic \$10 hotel we realised we had underestimated just how long Vietnam really is and decided to stump up for the airfare to Hanoi.

Upon leaving Australia we were told Vietnam is really warm, and "don't worry about taking a jumper or anything like that". Upon arriving in Hanoi we realised this sage advice, while true for the south, was totally wrong for the north. We quickly donned the lightweight jumpers we had brought for the plane and started looking for something warmer. Like a lot of people with CMT, my hands turn from semi-functional to useless lamb chops when they get cold, so keeping warm is a priority for me.

After a yet another \$10 hotel it's safe to conclude that for such a princely sum you can expect; a mattress made from plywood, plumbing (in various states of falling apart), WiFi (from the more expensive hotel next door), and a door. In Hanoi you can also expect a travel agency in the ground floor selling you tours of Ha Long Bay. We purchased a tour

from a company with the promising name of “Lemon Cruises” and jumped on a bus to Ha Long. Some time later we boarded our tender and put on our lifejackets (the crew were very insistent, this made us worried).

As it happened, our worries were totally unfounded. We arrived at our cruise ship (like a large houseboat) and settled into the best room we’d had all trip. The tour guide then took us on a whirlwind trip through a big cave, a floating fishing village, a mountain lookout and then back to our houseboat for a lesson in making spring rolls.

The real disaster happened a little after dinner time. We had been expecting something to go wrong since the life jackets and, sure enough, the crew announced in broken English that we were to do Karaoke. The Vietnamese really like Karaoke and the crew continued well after all the tour group had gone out into the chilly night air to enjoy what peace and quiet could be found there.

Over breakfast the following day we found out that we would be going for a bike ride and then to the main city on Cat Ba Island. We were in for a treat! After a series of boat trips we were each assigned a bike that had at least half its brakes working, and we set off into what we were told was hilly terrain. Within 2km, the beautiful concrete path became a construction site and we had some great impromptu fun helping the locals build their road, before continuing to a village where the mud houses had dishes for satellite TV and the dogs were... well... there were lots of puppies!

All too soon we were back on the boat and off to the main city on Cat Ba. \$4.20 later we had motorbikes for the afternoon, and we set off into the wild green yonder. We had been told of a cave in the heart of the island that had been converted into a bomb-proof hospital during the war. This mix of history and speology was too much to resist, and we headed through the blast door into a concrete Tetris of rectangular rooms. These spooky empty echo chambers once housed the injured Viet Kong, and now every tourist who enters can’t help but mentally fill each ward with beds and moaning and screams. By far this was the most interesting place we visited. To see such a man-made thing inserted into a mountain and now being consumed as stalactites form on the flat roof of the hospital inside the main chamber.

After a Vietnamese coffee (like Turkish coffee with condensed milk) we jumped, jittering, back on the bikes, and headed to a village down the road. It was getting cold by this point and the light was starting to fade, so I quickly took some pictures of a local furniture workshop and we belted back towards the city. At 70 km/h my hands started to get cold, and with “helmet” being a baseball cap with a chinstrap, we decided to stop and let my hands warm up. By the time we got back to our hotel, my hands were almost immovable. Looking back I’m quite glad I didn’t hit any big bumps or they might have come off the handlebars. We handed back the bikes in the dark, and headed to our hotel room for a long hot shower to warm up.

It’s funny how such a great experience can fit into two paragraphs. That afternoons motorbike ride, those three hours on rented scooters, have changed the way I see motorbikes from something that was in the “too dangerous” basket into the “WOW I want to do THAT!” basket. The challenge now is to find and or modify a motorbike to work with my CMT.

After that time on Cat Ba Island the rest of the trip was over in a flash of buses and planes, before we knew it we were eating ice-creams and waiting for a lift from the bus station.

At this point given the publication you are reading, I should probably reflect on something like tips for travellers with CMT. So I will...

1. Traveling with CMT is like daily life with CMT, but the beds are harder and people won’t necessarily speak English.
2. The best friend of the CMT traveller is a quality multi-tool like a Leatherman
3. Seeing people who are victims of landmines and Agent Orange really makes you appreciate the limbs you have!



COORDINATORS & SUPPORT GROUPS

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kayeCMT@iinet.net.au

NEW ZEALAND

Gaile Fornusek: 07 8686375 Email: fornuskova10@gmail.com

Would you like to join a CMT Support Group?

The Association is again organizing 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
CMTAA

THANK YOU for donations from 1st November 2013—31st March 2014

\$500 and over

Mr. John Speight

\$200 - \$499

Mrs. Hilda Newstead
Mrs. Colleen Bower

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Ms. Michelle Ehrich
Mr. Bruce Nolan

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Mrs. Helen Ward

Mrs. Margaret Psaltis
Mr. and Mrs. David Critchley

Please follow the steps below to donate to the CMTAA:

Step 1: 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

Step 2: Email us at cmtaa@email.cs.nsw.gov.au letting us know of your donation.

Step 3: Smile! Feel good about yourself! Your donation will go to help people with CMT.

KEEP AN EYE OUT FOR DONATION OPPORTUNITIES ON OUR NEW WEBSITE

CMTAA Committee (2013/2014)

Executive Members

President:	Darryl Beitsch (NSW)
Vice President:	Katherine Matthews (VIC)
Treasurer:	Robert Twin (ACT)
Secretary:	Anycie Berkmann (NSW)

Ordinary Committee Members

Newsletter Editor:	Jillian Critchley (NSW)
Legal Advisor:	Antonia Karydis (SA)
Joanne Liso (NSW)	
Ann McLaughlin (NSW)	

SEMINAR DVD's & VIDEOTAPES

September 2012

CMT Research Achievements—Prof Garth Nicholson
Dev'ts in the Management of CMT—Assoc Prof Joshua Burns
Clinical Psychologist— Helga Hemberger
Physiotherapy in prep for appropriate exercise—Dr Kristy Rose
CMT and Sport—Dr Che Fornusek
Presentation from Inaugural CMT Aussie Kids Weekend
Interviews with the CMT Community
CMTAA research recipient presentation

September 2011

CMT Research Achievements —Prof Garth Nicholson
Dev'ts in the Management of CMT—Assoc Prof Joshua Burns
PGD in IVF— Dr Don Leigh
The role of the Podiatrist—Karl—Heinz Schott
Personal Trainers and CMT—Gerry Fenyo
Interviews with the CMT Community

September 2010—Seminar, Sydney

CMT Research Achievements —Professor Garth Nicholson
An International Research Perspective—Dr Joshua Burns
Successful Podiatry for people with CMT—Ms. Anita Hood
Appropriate footwear for CMT sufferers—Mr Casper Ozinga
Success stories from children and adults with CMT

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

All contributions, letters, and enquiries should be directed to the Editor, CMT CoMmuniTy newsletter, 15 Naranga Aveue, Engadine 2233 N.S.W. or email: cmtaa@email.cs.nsw.gov.au

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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).

DID YOU KNOW?

The **National Public Toilet Map** shows the location of more than 14,000 public and private toilet facilities across Australia. Details of toilet facilities can also be found along major travel routes and for shorter journeys as well. Useful information is provided about each toilet, such as location, opening hours, availability of baby change rooms, accessibility for people with disabilities and the details of nearby toilets. There is a website and also an app available: <https://toiletmap.gov.au/>

Master Lock Access Key (MLAK) is a master key that fits into specially designed locks allowing 24 hour a day access to public toilets. Eligible people can purchase a key that opens all accessible toilets displaying the MLAK symbol. Eligibility is restricted to people who have a disability and a written authority is required from a health professional. To find out more, contact the Master Locksmiths' Association of Australasia on 1800 810 698 or 03 96459995

Have Wheelchair Will Travel is a website created by a Sydney family of six who has a son with Cerebral Palsy. The aim of the website is to share information on travel tips to other families who are considering travelling with children with a disability.

Information about Wheelchair tips, Airlines, Travel Insurance and Car hire are included on the site which can be found at <http://www.havewheelchairwilltravel.net/>



There are organisations throughout Australia (and beyond) committed to ensuring people with a disability are able to fully participate in many sporting and recreational activities. Try your state or territory Sport and Recreation Services.

The **Independent Living Centre** can show you and talk you through a range of aids for everyday life. Information about products and services to help people remain independent and improve their quality of life is available from the ILC in your state/territory. The ILC do not sell anything—what they have is knowledge and experience. Some of the products include aids for bathing, showering and toileting; eating and drinking; personal care; walking and standing aids; switches and remote controls; recreation, leisure and sports; office, workplace and school; and kitchen and household tasks. Check out: <http://ilcaustralia.org.au> or call 1300 885 886

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.

Deadline for next newsletter: 15th July 2014

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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

Email: cmtaa@email.cs.nsw.gov.au

THE CMTAA COMMITTEE WISH TO ADVISE THAT AFTER MUCH DISCUSSION WE HAVE DECIDED TO DISCONTINUE LISTING IN THIS NEWSLETTER THOSE DRUGS THAT MAY AGGRAVATE OR EXACERBATE CHARCOT MARIE TOOTH. WE SUGGEST YOU SPEAK TO YOUR MEDICAL PHYSICIAN FOR ANY FURTHER ADVICE ON THIS MATTER, CONSIDERING YOUR INDIVIDUAL CIRCUMSTANCES.

PLEASE NOTE: WHEN PAYING YOUR MEMBERSHIP RENEWALS BY ELECTRONIC FUNDS TRANSFER (EFT) REMEMBER TO MAIL YOUR MEMBERSHIP RENEWAL FORM TO CMTAA 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 .

KEEP IN TOUCH

Name: Mr/Mrs/Miss/Ms (please circle)

Address: _____

State: _____

Postcode: _____ **Phone:** () _____

Email: _____

Signature: _____ **Date:** _____

☐ **NEW MEMBERSHIP**
(\$33.00 per year) \$ _____

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(\$33.00 per year) \$ _____

DONATION TO RESEARCH \$ _____

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Donations \$2.00 and over are Tax Deductible.

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