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.

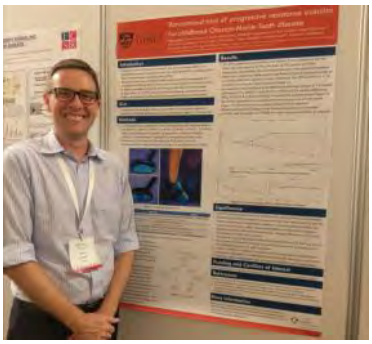
VOLUME 86 Winter 2017

CMTAA
Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

GROUNDBREAKING AUSTRALIAN RESEARCH FINDINGS:

EXERCISE IS MEDICINE FOR CMT



Prof. Joshua Burns presenting the exciting findings at the 2017 Peripheral Nerve Society Annual Meeting, Sitges-Barcelona, Spain this month.

Charcot-Marie-Tooth disease is a term used to describe a broad range of inherited genetic disorders, known as 'neuropathies', that affect the peripheral nervous system. The disease, which affects approximately 15,000 Australians, causes a myriad of motor and sensory impairments but the most debilitating impairment is foot and ankle weakness. The weakness in these muscles often causes painful foot deformities (such as pes cavus or highly arched feet, hammer toes), lifelong difficulty performing everyday tasks (such as walking and climbing stairs) and injuries resulting from trips and falls.

There is no cure for CMT and while treatment (which involves leg braces and orthoses, specially designed shoes, surgery, physiotherapy such as stretching and occupational therapy for hand problems) helps to manage some symptoms, it does not have any effect on muscle weakness.

Excitingly though, a recent trial led by Professor Joshua Burns, Director of our Paediatric Gait Analysis Service has found the very first effective therapy for reducing muscle weakness in CMT patients. The study published in The Lancet Child & Adolescent Health, which is the first of its kind in the world, found that 6 months of moderate-intensity progressive resistance exercise can help not only slow the progression of muscle weakness in children with CMT by up to 30% compared to patients who did not exercise, but also strengthen their muscles over a 2-year period. It was also a safe treatment.

Prof Burns' 9-year program of exercise research performed across Sydney Children's Hospitals Network, University of Sydney and University of NSW South Wales and culminating in a randomised clinical trial specifically focused on exercises that targeted the muscles in the feet but the success of the trial now means that exercising other affected muscle in the body are also expected to be safe and beneficial.

For patients with CMT, the results of the trial are life-changing, helping to not only improve their chronic pain and reduce the degree of disability but also greatly helping to improve their quality of life. Targeted exercise has already started to be implemented in treatment plans at our Hospital and is hoped to be adopted into treatment guidelines both nationally and internationally in the coming months.

With thanks to Prof. Burns

INSIDE THIS EDITION

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

NEWS FROM THE REGIONS AND STATES

A.C.T.

Hello from Canberra, where we are already getting a foretaste of chilly winter nights!

The ACT & Region support group held our quarterly meeting on 15 March. As usual, it was a small group with lots to talk about and lots of laughs. We had two guest speakers for the evening, both of them from within our group. Extraordinarily, they had both received results of DNA tests from Prof Garth Nicholson since our previous meeting – and both had been told that they don't have CMT! Not a good result for the augmentation of our group, but it was fascinating to hear their stories.

The first speaker had been diagnosed with CMT by a neurologist 17 years ago. Admittedly, her symptoms had not followed the usual CMT pattern. She had started with frequent unexplained falls, followed by a fairly rapidly progressing paralysis of both legs. Her correct diagnosis, confirmed by DNA test, is hereditary spastic paraplegia.

The second speaker had received his CMT diagnosis in more recent years and appears to have many of the typical symptoms, though he is obviously more mobile than others in the group. However, Prof Nicholson is of the opinion that his peripheral neuropathy is not CMT, but a side effect of another medical condition.

The stories we heard underline the importance of consulting the expert. Neurologists may think they're seeing CMT, but, if there's no known family history, it needs to be confirmed by Prof Nicholson.

On Friday 30 June the Canberra & Region support group had our first meeting in a venue more centrally located than my home. We met at the Southern Cross Club Woden, where we had been given the use of a meeting room. There were a few teething problems with the setup, but we eventually got everything working. The advantage of using the club was that we could have dinner together before the meeting.

Robert Twin, the CMTAA treasurer, briefed us on the association's new strategic plan. This prompted a lot of discussion and many interesting suggestions for improving public awareness of CMT. We also watched Prof Garth Nicholson's presentation to the 2016 Awareness Day, in which he explained the latest areas of research, which offer a very exciting hope of a cure for CMT.

We will meet again in late September or early October and hope that some who haven't been to a meeting yet will join us!

Gabrielle Evans, ACT State Co-ordinator

WESTERN AUSTRALIA

The WA branch of the CMTAA had a very successful meeting on Saturday 29 April when Tessa Jupp RN from the Post-Polio Network of WA Inc addressed the group on 'The Many Faces of Fatigue'. Once again, she provided the group with lots of information and advice geared to addressing some of the problems and issues suffered by those with CMT.

We welcomed quite a few new members to the meeting and once again, it was great to hear the amount of information being exchanged between the group – and many thanks to Amy who took the time to provide us with information to groups and websites she had found useful and which was subsequently circulated to our members and is provided below.

Our next meeting is being planned for **Saturday 26 August 2017** – final details to be circulated nearer to the time.

Lastly, many congratulations to one of our members, Jimmy Mouritz, who has been accepted into the state wheelchair rugby team and is about to embark for his first week of training.

1. Online support group via Team Inspire (need to create an account by clicking on 'Join'): https://www.inspire.com/groups/charcot-marie-tooth-cmt

2. The Hereditary Neuropathy Foundation (USA): http://www.hnf-cure.org and http://www.hnf-cure.org/charcot-marie-tooth-tool-kits (can download symptoms checklist and neurotoxic drug list from this webpage):

3. CMT Association (USA): https://www.cmtausa.org and https://www.cmtausa.org/product-category/publications (link to buy CMT '101 Practical Tips' book.)

Kind regards, CMT WA Committee

NEWS FROM THE REGIONS AND STATES

VICTORIA

It has been 16 months since I volunteered to be the Victorian Coordinator and I am happy to say I have got to know a few of you. We have had a range of events in that time, from coffee catch ups to lunches, a mobility workshop and fantastic seats to see Kooza, an amazing show by Cirque du Soleil. In the coming months we are planning another mobility workshop as well as a visit to the Independent Living Centre, I also plan to squeeze in a brunch when the Melbourne weather warms up a little, so keep an eye on your emails and facebook for up-dates on the events. If there are other events that people would be interested in please feel free to contact me and we can certainly add them to the calendar, my contact details are on the CMTAA website under support groups.

I thought I would take the opportunity to share a little bit of my journey with CMT. I was first diagnosed as a twelve year old and over the years I have struggled with falls, sprained ankles, numerous surgeries, and decreased sensation in hands and feet. In order to stay as strong as possible I do regular exercise; swimming, strengthening exercises with a Personal Trainer, yoga and bike riding. I have had a 40 year journey of coming to terms with the challenges of CMT, I have gone through the emotions of denial, frustration, anger, hopelessness, despair and finally acceptance. Over the years I have noticed the lack of awareness of CMT, not only amongst the general public but also the medical profession, and I now find myself in a place where I wish to help others on their journey with CMT and hopefully make them feel as though they are not on their own. I look forward to hearing about the experiences of others with CMT over brunch, coffee or at one of the events we are planning for the coming months. I also plan to be at the seminar in Sydney on the 24th September and it would be lovely to see you there.

In the meantime, do keep warm through this cold Melbourne winter!
Regards, Paula Hodgson, Victorian Support Group Coordinator

TASMANIA

Dear CMT folk

We're now in the grip of winter with very cold days and we've already had two days of snow at our place along with heavy frosts making driving very difficult. David and I have just returned from 9 weeks on an "outback experience" where we had temperatures in the high 20's and low 30's for 8 of those weeks. Outback Australia is an amazing place and I encourage folk to go visit and see the resilience of our farmers and cattlemen as they face drought, heat and pests. We could all learn a thing or two from them!! I hope to organise another Get-together for our Tassie folk in the near future but will leave it until the weather warms up a bit. I'm looking forward to taking part in a study in Sydney of hearing loss associated with folk who have CMT. Hopefully the audiologists can learn something from this and be of help to other folk with neuromuscular problems. Keep up to date with all things on the CMT website as your committee work hard to improve treatment and research for CMT.

Kind Regards, Marilyn Kremmer
Tasmanian State Coordinator

SUNSHINE COAST

The most helpful info I have received lately, is from a physio at the Knee Joint, Warana Sunshine Coast. He had me walking like a "lady" - it was hilarious when he demonstrated, especially 8as he is a slightly portly gentleman, and did it with both hands sticking out like the old June Dally Watkins deportment classes of last century!!!

No looking down (due to balance problems), no hurrying (as I always do), and the main instruction was tighten ab muscles and glut muscles. AND IT WORKS!!! Now when walking, I have to keep thinking "belly, bum".....

Best Wishes to all, Aileen Harrison
Sunshine Coast Area Co-ordinator

NEWS FROM THE REGIONS AND STATES

NEWCASTLE

Hi all, Our first meeting for 2017 was held on the 27th May. It was great to see our regular members attending and any new members who would like to attend are most welcome. These get-togethers are a good opportunity to meet and discuss things in a relaxed, friendly environment as we can all learn from each other.

I'm planning another meeting for late August or early September. If you would like to attend a meeting or need further information I can be contacted on 0412 891 647.

Kind regards, Gabby Cosgrove
Newcastle Co-ordinator

SOUTH AUSTRALIA

A big hello from SA. What lovely hot weather we had to now very cold! Hope everyone is keeping warm, coping and adjusting well. Since last issue, the CMTAA Inc., SA Support Group has held another meet & greet in May at Kibbi's in Christies Beach.

An enjoyable afternoon with great coffee and pancakes sharing stories with members about their travels. Our next Coffee & Chat will be 19th August 12-2pm, at Monica's Dine Inn at Blakes Crossing in the Northern Suburbs. Mark your diaries and be sure to come along and meet with other fellow SA CMT community members.

Happy to report a strong interest on the local CMTAA Inc., the CMTAA Inc. Support Group Facebook as it continues to grow to 50, gaining 7 new members in the last quarter. The SA CMTAA Support Group continues to increase CMT awareness.

A big thank you to Lisa for pursuing our application with Grill'd Norwood to have a fundraising jar for the month of June. We are pleased to announce we achieved 2nd place, securing CMTAA Inc., a $100 donation. The SA CMT Support Group wish to thank all for spreading the word and increasing CMT awareness and raising the profile of CMTAA Inc., to the SA community at large. A sincere thank you to Grilled Norwood for their support.

As a lead up to CMT International Awareness month the support group are busy arranging radio interviews in both August and September. We are planning our SA CMT Support Group team entry once again to take part in the City to Bay fun run September 17, attend the CMTAA Inc., national seminar in NSW. Depending on interest we are planning to hold a short informational session also in the first week of September. So, keep an eye on the CMTAA Inc., website and Facebook, the SA CMT Support Group Facebook as well as your incoming emails for further details. Finally, we will again plan to have a stand at the Disability & Ageing Lifestyle Expo but this year it is on 27 October.

I would like to encourage our SA CMT Community to make contact with us by attending one of our planned events or by calling us. All SA contact details for the Support Group are available on the CMTAA Inc., website.

Finally, we would like to finish up with a great story about young James living a dream. James was lucky to attend MDASA Camp Quality in April and as part of the program he was given an opportunity to ride a Harley Davidson. Go James… Take care all and keep on moving!

Warm regards Antonia, Lisa, Simone, Isabella and Andrea.
Your CMTAA Inc. SA Support Group.

A Member's Story

"So what happened with your legs", the GP doctor asks as I enter his room to discuss a totally unrelated matter.
"I have CMT," and roll up my pant leg to show him my orthotics. "It's called Charcot Marie Tooth" and wait for acknowledgement and recognition that doesn't come.
"It's a neuro-muscular condition that is also known as peroneal muscular atrophy," I elaborate. "Oh yes," he says as he searches his mental database for long forgotten details contained in his textbooks.
So, how can I help you today as he quickly moves to the matter at hand.
It is yet another instance, of many over the years, of having a condition few people have ever heard of.
Growing up in a small mining and forestry town in Northern Ontario in Canada in the 50s and 60s my condition was undiagnosed and unrecognised. I simply walked funny as far as everyone was concerned.
Even if I had known the symptoms and had explained to my mates that the reason I walked funny was because my condition causes foot drop, they would have laughed at me and told me not to be careless in dropping my foot and just pick it up.
So basically from the age of 14 or so until I was in my late 50s, I adopted the attitude of just getting on with it. Mentally, I also started to file activities into my own cando and cantdo mental database and took the attitude that there is nothing I couldn't do until I couldn't do it.
Even then, I refused to accept the obvious. I played basketball at high school and got picked for the team not for any particular skills but simply for determination.
I also played the Canadian version of American football. The issue was where to place a skinny kid who couldn't run. The coach of the team came up with the bright idea of putting me in the centre when we were winning by double figures.
If you have never seen a North American football game think of those big bruisers in the front row of a Rugby League game or Rugby Union game. My job was to pass the ball between my legs to the quarterback and stop a 120kg giant from running over my 46kg body and tackling the quarterback. In my brief and only appearance on the field, I managed to stop him going forward not through any innate skills of mine but simply that he tripped over me.
I reluctantly had to put this activity into the cantdo column not least because of CMT.
My working life was also filled with CMT adventures. In Canada, I worked every summer from the age of 15 to 20 in a variety of jobs including being a lumberjack, working in a saw mill, a mining site and building concrete public sidewalks.
As far as I was concerned there was nothing to prevent me doing any of those things and I acquitted myself reasonably well although I did once fall into freshly poured cement on a sidewalk when I tried to walk on a narrow beam along the cement pour.
Personal CMT failures like that cement pour are easily brushed away and forgotten. But, working as a tradie was inevitably put into the cantdo column.
At the ripe old age of almost 72, I can look back at my CMT journey and realise I did not miss out on anything I wanted. I have travelled the world including climbing up the Great Wall of China, I have a wonderful and supportive family and while tight wire walking is obviously beyond me, I am still working using a computer and life is good.
I also do not believe that the CMTooth fairy will magically improve my condition anytime soon and therefore go to the gym twice a week to strengthen what muscles I have left in my legs and arms.
Over the years I have of course amassed a great number of frequent falling flyer points and a few bruises here and there but that comes with the CMT job.
While my cando list narrows not least because of advancing age, I still contemplate jumping out of an airplane. After all what are falling flyer points if you haven't by now learned how to hit the ground.
The only thing stopping me is the hallelujah chorus in my house that sings in a united voice to tell me not to be a bloody idiot.
John Arbouw

Invitation to actively support your CMTAA

In our Autumn 2017 Newsletter I detailed the progress we have made in adopting our first Strategic Plan. I concluded that article with the suggestion that anyone in our CMT community can contribute to our success in achieving our goals through furthering the strategies identified. I would now like to expand on how this can occur, and to explain how your Committee is approaching the task.

Many of you may have started to read the document circulated with the last newsletter, and you may well have felt overwhelmed by its scope. This is understandable and you are not alone; however this is the price of progress if we really wish to make a difference.

I wish that you could have participated in our Planning Day back in October, because then you would have experienced the buzz in the room and have shared our enthusiasm to make things happen. We are a small Committee and all are already delivering on parts of our plan. So given our other roles this small team will struggle to do justice to the scope of the directions that we have now set.

Your Committee is currently assessing how we will manage progression of the strategies and how best to facilitate member input to this process. The first step has been to document the tasks in the form of a table which can track those under active consideration. This means we have identified someone to manage a strategy; have proposed an approach which can be put to the Committee for approval; and finally to monitor progress.

At present this is taking place at our six weekly Committee meetings through a revised Excel table emailed to each Committee member; however this is not conducive to expanding the opportunity for participation by our broader membership. For those of you who are connected to the Internet the name 'Google' will be familiar. As well as providing a reliable way of discovering information, Google provides a range of on-line collaboration tools. One of these is 'Google Sheets'. This is like Microsoft Excel, but with the capability of a spreadsheet being manipulated by many participants at times that suit them. You may well be a regular user in another situation.

It's proposed that we publish our Strategy Management Table through this facility so that it is accessible to you in real time, to both review and to add to as appropriate. In a few weeks all visitors to our web site at www.cmt.org.au will be able to review the document; however permission to contribute will be reserved for members who request such access. We are hoping that at least some of these members will also be prepared to take on a strategy management role.

Initially I proposed to manage this process through responding to requests to be a participant. All members of CMTAA will be able to review the progress being made, and those of you who request collaboration access can provide me with their gmail (Google email) addresses so that I can set this up. If you don't already have a gmail account then visit https://accounts.google.com/signup. The email I will use for such requests is Strategies@cmt.org.au.

Through implementation of our Strategic Plan CMTAA will be able to work towards our vision of 'A World without CMT'. I look forward to collaborating with you in this way.

Robert Twin

PRESENTS
The 2017 National CMTAA Seminar

Sunday, 24th September 2017 @ Concord Medical Education Centre, Bldg. 26, Hospital Road, Concord NSW

Registration from 8:30am. Morning Tea available. Speakers start 9:30am.

Speakers include:

- **Professor Garth Nicholson, Neurogeneticist – Update on CMT research**
- **Professor Joshua Burns – Management of CMT**
- **2JJJ Radio personality Nas Campanella - Her personal journey.**
- **Pedorthist Karl-Heinz Schott – on Footwear and Orthotics with display by Shoe Tech**
- **Occupational Therapist Mandy Hanna – School Therapy Team, St George Hospital**
- **Jo Vercoe - Disability Services Worker from University of Wollongong**
- **Psychologist Melinda Myers – Living your Best Life Despite Challenges**
- **Dr. Alison Shield – Ass/Professor in Pharmacy, Canberra University - Effects of Medication on CMT patients.**
- **Dr. Scott Denton – Post Doctoral Research Associate, Uni. of Sydney – Results of Reducing the Health Burden of Charcot-Marie-Tooth Disease in Australia Survey.**
- **CMT Aussie Kids presentation**
- **Orthotics Display by Neuro Muscular Orthotics of Melbourne – Darren Pereira.**

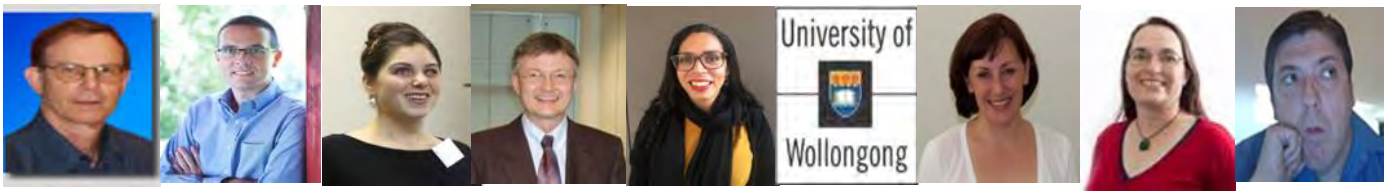
And for the first time a morning session for young people called 'Kids Matter'. Run by kids with CMT, about kids with CMT, for kids with CMT, with PIZZA included!

Cost (including Morning Tea and Lunch) **Adults: $35 Child: (18 years and under) $10 per child Family: $80 (2 adults and their dependent children under 18)**
This includes an attendee kit, morning tea, lunch and light refreshments.

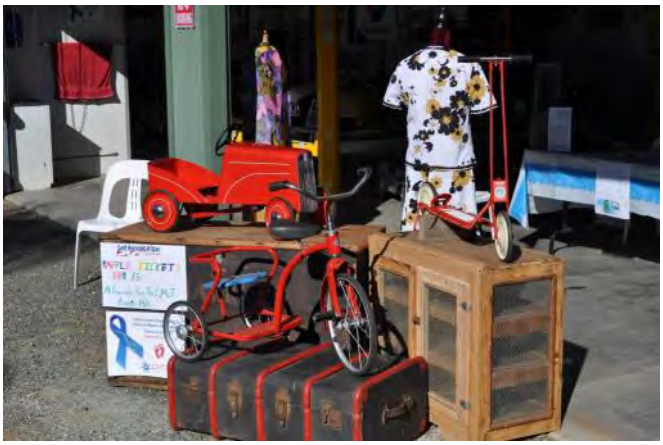
Parking is conveniently available in the hospital car park opposite the entrance to the Concord Medical Education Centre. Concession parking cards will be available when registering to enable you to park all day for $5 which is payable when exiting the car park. Limited disabled parking is available directly in front of the Concord Medical Education Centre. Just drive through Gate 3.

Please register your attendance through the Seminar RSVP link at the end of the Sydney Awareness Day Seminar article on the CMTAA website or by emailing cmtaa2@cmt.org.au or phoning the National Office on 02 9767 5105 by September 19th to register your attendance and pay on the day.

A Certificate of Attendance for professional development will be available if required.



Johnny's Open Day in Deniliquin



When Sarah McIntyre was selected to go on "The First Feet- A CoMTiki Adventure" she was extremely lucky as she had an extended family that supported her but more importantly a fantastic local community. Sarah lives in Winston Hills in Sydney but spends every holiday in Deniliquin with her Grandparents John (Johnny) and Denise Thomas. Denise has CMT 1A and myself and my two brothers Paul and Simon also have it. Kim, my sister doesn't have the gene, but is a great organiser.

When we were thinking of fund raising ideas we all wanted to spread the word about CMT and let the Deniliquin community know what it is and how it affects our family and that we can all help and support CMT research.

Our main idea was a raffle that has been a huge success. Johnny donated a 1940's "Chevrolet" Pedal car as first prize, 1963 Cyclops Tandem Trike and a Pilgrim "Hi-Speed" Scooter.

On the June Long Weekend Johnny opened up his amazing shed which is full of GT Falcons, Pedal cars, Trikes, Automobile memorabilia and loads of other old stuff that brings back so many memories. We had models parading many original vintage clothes from the 50's through to the 80's, there was something for everyone.

About 150 people came from the surrounding Car Clubs and enjoyed a sausage sizzle and afternoon tea. The generosity and response was overwhelming, on this day alone we raised $3500.

The raffle continues and will be drawn on the 17th November 2017; I will be at the Sydney Seminar on Sunday September 24th selling tickets. The peddle car, trike and scooter has bought so many memories to people and has been a great way to spread the word about CMT.

We as Sarah's family hope to raise heaps of money to send the 10 Aussie Kids to the UK next year but we also want to help raise much needed funds for research. Kids with CMT in Australia are so lucky that they have access to the camps and that so much research is occurring right here. I know that Sarah and the 9 other Aussie kids will be great representatives for all of us with CMT.

Warmest regards Kylie McIntyre

Auditory Neuropathy Research Study Recruitment

Some people with Charcot Marie Tooth can experience hearing difficulties as part of their CMT, particularly in the presence of background noise. The type of hearing loss seen is called auditory neuropathy (also referred to as auditory neuropathy spectrum disorder).

Auditory neuropathy is uniquely different to the typical type of hearing loss that occurs with age, and hearing aids are not always as helpful as we might expect. This means we need to "think outside the box" and research different ways of testing and managing this type of loss to try to improve outcomes.

Dr Kirsty Gardner-Berry and Jordan Claude are audiologists currently conducting research in the area of hearing loss in adults and children due to auditory neuropathy at the National Acoustic Laboratories (NAL) in Sydney.

What will this study focus on? The main aim of this research is to try to better understand the mechanisms underlying auditory neuropathy in individuals with this condition. The results from the study may help to guide future research into new testing techniques audiologists can use to assess patients in the clinic, and hearing aid program settings that are more likely to help.

Who is eligible for the study? If you have CMT and are experiencing difficulty hearing what people are saying in both quiet and noisy places you may be eligible. Some people describe this as being able to hear people speaking, but it not being 'clear' what they are saying, and they need to face people in order to understand them.

It would be helpful if you have already had the auditory brainstem response (ABR) test to confirm you have auditory neuropathy, but we can consider arranging this additional test for you if needed.

If you would like more information you can contact either Jordan Claude or Dr Kirsty Gardner-Berry
Jordan Claude: Jordan.claude@nal.gov.au Masters of Audiology candidate
Dr Kirsty Gardner-Berry: Kirsty.gardner-berry@nal.gov.au Ph. (02) 9412-6885 BSc. M.Aud. MASA (ccp)
PhD – Research Audiologist

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28th ANNUAL GENERAL MEETING

Sunday, September 24th 2017
3.00pm,

Concord Medical Education Centre, Building 26,
Entrance through Gate 3, Hospital Road, Concord Hospital, Concord NSW

Note: Parking is available in the Hospital parking area directly opposite Gate 3.
Limited Disabled parking is available by driving through Gate 3 and parking right in front of the Concord Medical Education Building.

AGENDA:

CONFIRMATION OF MINUTES OF 2016 AGM

PRESENTATION OF ANNUAL REPORTS

PRESENTATION OF ANNUAL FINANCIAL REPORT

ELECTION OF EXECUTIVE COMMITTEE

ELECTION OF AUDITOR

There are 7 positions on the Committee – four executive and three general.

Positions available that you can nominate or nominate someone for:

President

Vice President

Secretary

Treasurer

Committee Member

Committee Member

Committee Member

Please use the Nomination or Proxy form attached to nominate or vote by proxy for a person.

NOMINATION FORM

I …….. (Mr. Mrs. Ms.) Please indicate.

of ……..
(Address)

being a current financial member of the Charcot-Marie-Tooth Association of Australia Inc., wish to nominate for the position of: President, Vice President, Secretary, Treasurer, Committee – 3 positions. Please indicate below which position:

Position: ……

1st Member's signature ……

2nd Member's signature ……

Signed: …… Date ……

If you are not able to obtain a second member's signature, this can be done by the office secretary at the National Office, Concord.

If you are not attending and wish to appoint a proxy, please fill out the Proxy Form below.

FORM OF APPOINTMENT OF PROXY

I, ……..... (full name)

of, ……..
(address)
being a current financial member of the Charcot-Marie-Tooth Association of Australia Inc. **hereby appoint**

……
(full name of proxy) of

……..
(address of proxy)

being a current financial member of the Charcot-Marie-Tooth Association of Australia Inc., **as my proxy to vote for me on my behalf** at the Annual General Meeting of the Association, to be held on September 24th, 2017, and at any adjournment of that meeting.

…….. Date: ……
Signature of member appointing proxy

Note: A proxy may not be given to a person other than a current financial member of the Association.

FUN-DRAISING FOR CMT

Amelia Hill is a 15 year old normal teenager with CMT 4C. She has recently undergone major surgery on both her legs at the Women's and Children's Hospital Adelaide. She had Bilateral triple arthrodosis, tibialis posterior tendon transfers and archilles tenotomies. She then had 6 weeks with both her legs in casts and didn't weight bare. She has just transferred to moon boots for another 6 weeks while she is recovering and having new AFO's made. Amelia has continued with her secondary schooling during this time using her electric wheelchair to get around.

Amelia is 1 of 3 children, having and older brother and sister. Neither her parents or siblings/relatives have CMT. She is a bright and happy child who always has a go at anything that she can and looks forward to a bright future-whatever it holds!!!! Amelia is registered to attend the upcoming CMT Aussie Kids Camp at Cockatoo Island in August this year. She is particularly looking forward to meeting other children with CMT as she has never come in contact/seen another person with CMT.

After reading the last CMTAA Newsletter's article saying that research money was minimal and funds were low Amelia sprung into action. She organized {along with her family} a raffle and BBQ at the local tennis club opening day and raised $1084.75 for research and awareness of CMT. Her school is holding a casual dress day with a gold coin donation in term 3 to support CMT. Her cousins are also holding a casual dress day at their small rural school at the end of term 2 and donating the money to CMT. She would like to encourage you all to think about ways to raise money and awareness for CMT. After all that is what links us all together!!!! **Lisa Hill**

BBQ FUNDRAISER FOR CMT AUSSIE KIDS UK TRIP

Cousins Eleanor and Maddy Critchley have been selected as part of the CMT Aussie Kids touring group 'The First Feet' travelling to the UK CMT camp next July, and wanted a way to both educate their local community about CMT, but also highlight the challenges they face everyday living with the condition. What better way to do this than with a Sausage Sizzle and Cake Stall at their local markets in southern Sydney. The girls, in Year 9 at Engadine High School approached the P & C and Student Rep Council who got behind the event, providing student and teacher volunteers on the day.

The home baked goodies and sausages were a hit and the girls, supported by their family and school, raised over $700 in one morning. They set up a display of photos from previous CMT Aussie Kids camps, along with brochures and posters on CMT, and answered questions on their condition to a range of interested market-goers.

Eleanor and Maddy have plans for other fundraisers, with the focus being on education and awareness of their disability. They still have a long way to go to fundraise to their goal of $5000 each, but are determined to reach out to the wider community, showing a positive attitude to their disease.

With knowledge comes understanding.

STEPH DAVIS LEADS AWARENESS CAMPAIGN FOR CHARCOT MARIE TOOTH

Reprinted with kind permission from Toby Vue and the Yass Tribune

I used to fall over all the time. I can't run, or hop, I struggle with jumping, and my handwriting is unreadable at best," writes 18-year-old Steph Davis, who is living with Charcot Marie Tooth (CMT). For many people, the diagnosis of (CMT) comes as a shock. For Ms Davis, though, she said "it really didn't bother" when she was diagnosed with the disease.

She was nine.

"It was something that was hard to explain to other people, but it also answered a lot of questions," she said.

Research has indicated that as many as one in 2500 people in Australia could have CMT. While it is not life threatening, people with CMT have it for life. The disease causes slow degeneration of the peripheral nerves including feet, legs, arms and hands as muscles weaken due to the loss of stimulation by affected nerves. It is an inherited neurological disease with no known cure, and the severity and symptoms can vary.

For Ms Davis, it took specialists six months to diagnose her with the condition.

"Because it affects people in different ways, it often gets misdiagnosed. The only person I knew who had it at the time was my mum – she found out when I did," she said.

Between 2011 and 2016, Ms Davis had two operations. The first lowered her arches and partially corrected her walk to minimised her falling. The second corrected her hammer toes by fusing joints, shortening bones, moving tendons and placing wire in eight toes.

On June 17, 2017, Ms Davis organised and held a trivia night at the Yass Golf Club to raise funds to take part in the 'CMT Kids UK Trip' in July 2018. About $2150 was raised in the end, with individuals, community organisations and businesses playing their parts.

She organised and conducted the event all the while studying in her final year of high school. "There were at least 100 people on the night," she said.

Jillian Critchley, committee member of CMT Association Australia (CMTAA), and her family drove from Sydney to Yass to attend the fundraiser as a surprise.

"We wanted to show our support for her hard work. It's been a labor of love for her to help the cause," Ms Critchley said.

The CMT Kids Weekend in the UK will provide a supportive environment for children and young people with the condition. It comes after the inaugural event in Australia where 10 participants from the UK visited Australia.

"It's about helping them look at their abilities, not disabilities; it's to say 'we can't feel sorry for ourselves and we can do a lot if peers and family encourage us'," Ms Critchley said.

"They are kids, but they will turn into adults, so we're giving them the tools to look after themselves."

Ms Davis said she looked forward to meeting old and new friends in the UK.

"I made some good friends last time and it'd be great to see new people over there. The main thing is to build connections," she said. Her goal of the trip is to spread awareness. "I just hope more people can learn about it. Not many know what is and how it can affect people," she said.

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NEW ZEALAND

Vacant

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NEW ZEALAND *Vacant*

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

CMT Aussie Kids is a youth program run by the CMT Australia. It supports kids with CMT and gives them opportunities to 'play' as equals with peers with the same condition, learning to manage and **respond positively** to the difficulties and challenges they confront every day.

In July 2018, **ten CMT Aussie Kids** are heading over to the UK to attend a 4 day CMT Kids Camp in Keswick, Cumbria, getting to know their British CMT counterparts and touring the country for 2 weeks.

We have created a **GiveNow donation page** where family, friends and supporters can donate to help make our trip a reality.

Go to

https://www.givenow.com.au/cmt

NOW AVAILABLE

CMTAA SEMINAR 2015 DVD

Prof. Garth Nicholson – CMT Research and Achievements

Mr. Michael Carroll: My Life with CMT

Dr. Manoj Menezes – CMT in Childhood: Trials and Interventions

Dr. Scott Denton: Reducing the Health Burden – project update.

Workshop: Prof. Garth Nicholson, Prof. Joshua Burns and Mr. Darryl Beitsch

CMTAA SEMINAR 2016 DVD

Prof. Garth Nicholson – CMT Research and Achievements

Dr. Desmond Soares, Surgical procedures to benefit hand, foot and ankle problems.

Mr. Darren Pereira, Orthotist: The use of Orthotics in Managing CMT

Mr. Ernie Tye, Pedorthist: Custom Appliance Application Based Footwear

Question and Answer Session: Professor Garth Nicholson

These newly released DVDs are available from the National Office for $25 each (including postage and handling). Order your copy now by phoning (02) 0767 5105 or email: cmtaa2@cmt.org.au

SEMINAR DVD's & VIDEOTAPES

October 2014

Prof Garth Nicholson—CMT Research and Achievements
Prof Joshua Burns—Developments in the Management of CMT
Dr Andrew Wines—The surgical management of the foot and ankle in CMT patients
Lyndal Douglas—Genetic Counselling
Lois Tonkin—Principles of Pain Management
Judy Gates, Gavin Fernandes, Leanne Huxley—Posture and Balance Workshop
Young CMTers—CMT Aussie Kids Weekend

October 2013

Prof Garth Nicholson—CMT Research Achievements.
Assoc Prof Joshua Burns—Developments in the management of CMT
Dr Alison Shield—General Principles Regarding Medication and CMT
Rebecca Howard, Senior Occupational Therapist, Independent Living Centre—Technology to Improve CMT Quality of Life

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 Pedorthist—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 Avenue, Engadine 2233 N.S.W. or email: cmtaa2@cmt.org.au

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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 2017

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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

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Charcot-Marie-Tooth Association of Australia Inc.

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

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