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.

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CMTAA
Charcot-Marie-Tooth Association Australia Inc.

# The CMT CoMmuniTy

## AUSTRALIAN RESEARCHERS APPOINTED TO INTERNATIONAL CMT BOARD

Wonderful Congratulations to Professor Joshua Burns and Assoc Professor Marina Kennerson for being elected to serve on the CMTR board. The CMTR's mission, as part of the Peripheral Nerve Society, is to improve the life of patents with hereditary neuropathies by advancing care, promoting research and training of clinicians, basic scientist and other health professionals interested in inherited neuropathies. This will be achieved by focusing on three areas; care, research and education. These 2 CMTAA Grant Recipients will interact with other members from across the world, including Mike Shy from the US and Mary Reilly from the UK.

Assoc Professor Kennerson said: 'The election of Josh and myself onto the CMTR board means that we will actively be able to help shape the direction of international clinical and basic research for CMT that will mutually benefit patients clinicians and researchers. To have two Australian representatives is very good for the region and recognises Australia's international, national and local sustained contribution to research and CMT patient care.'

She continued: 'Personally, I have spent all of my career doing research for CMT and I am thrilled that I have this opportunity to contribute my years of experience to maintain and continue to build a positive future for CMT research through my role on the CMTR board'.

These appointments demonstrate and acknowledges the world class researchers we have here in Australia. The CMTAA is proud to be associated with Josh and Marina and wish them well with their appointment.

### INSIDE THIS EDITION



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

# PRESIDENTS REPORT

**Dear CMT Family**

Well 2018 seems to have just started and already we are a quarter of the way through. I hope your year has started off well. My early months as your President have been quite busy as I get myself around all that is going on in the CMTAA. Your committee has a lot planned for the remained of the year including:

* Our National Seminar day which is to be held this Year in Hobart

* Our CMT Aussie Kids trip to the UK

* Holding a stand at the Sydney Disability Expo in May

I have spent a bit of time over the last few months getting to know the Association and the wonderful people in it including holding conference calls with the Support group coordinators in WA, SA, VIC ad QLD and I have also been able to visit in Adelaide. I have also participated in events with Genetic Alliance Australia.

We have recently completed a review of our fundraising activities to ensure that our receiving of donations and other activities complies with the different legislation in every state. As a result, we have registered as a fundraiser in all states where necessary. While I hope to publish a guideline on how we can ensure that we don't run afoul of the law I would ask that you all check with the office before you undertake any form of fundraising for CMTAA so we can make sure that we have ticked all the boxes. This is not a difficult exercise but can be a bit tricky so please check.

Over the summer, I read a new memoir by Bethany Meloche on her experience with CMT in her new book called "How should a body be?" . While every person's experience with CMT is different I found myself reliving many similar experiences I have had, especially her story of dislocating her knee cap (ouch). It is an easy and enjoyable read. I did, however, have a few issues with both her story and some of the claims in the book. It is clear that her family were in denial about the possibility of her having CMT (even though her father and grandmother had it) and actively hid it from her. Again, people may disagree with me, for me the best approach to managing CMT is a personal active approach which would involve starting remedial exercise as soon and as young as possible. Professor Josh Burns' work has indicated a possible significant improvement in outcomes with early intervention. The second issue were 2 claims implied by the book. These were that there was a link between CMT and gastro-intestinal problems and the second was that CMT1A gets worse with each generation. I checked both these with Professor Garth Nicholson who confirmed that these were both inaccurate. So, while I got a little angry reading the book for the reasons above I did enjoy Bethany's inspiring story and can recommend the book.

Your committee is a great group of very committed people but could always do with a hand. If there are any ways you think you could help (even if only a little) please don't hesitate to put up your hand.

Have a great year and be kind to yourselves.

Tony

CMTAA President

# NEWS FROM THE REGIONS AND STATES

## TASMANIA

David and I have just had a wonderful couple of weeks holidaying on the east coast at Coles Bay and then Bruny Island. Some of you may know these areas. Tasmania badly needs rain as it has been an exceptionally dry summer – good for those on holidays but not so good for the farmers.

Big year for Tasmania as we host the CMT National Seminar on 15th September. This is the first time for Tasmania so Tassie folk let's do this!! As you can imagine it has been a busy time organising a venue, getting costings, etc. My thanks go to the Muscular Dystrophy Association for their financial assistance to make this possible. I look forward to as many of you as possible attending as it's a great opportunity to hear world class speakers and meet other folk with CMT. I hope to have another "Coffee and Chat" before this as we have several new folk who have joined our Support Group. Kind regards, Marilyn

## GOLD COAST

Hi, Greetings from Judy on the Gold Coast, hope everyone is well and coping alright. Good news, I'm finally out of the moonboot and wearing my new AFO and surgical grade shoes, which means that they were specially made for me after my tendon transfer. Being in a moonboot it is taking a little bit of time and effort, but I can see a slow improvement in my mobility.

Anyhow, enough about me! The meeting the other week was a great success, had a great attendance for awhile, with three new couples turning up. We had a great time, and we all stayed for lunch. I am now in the process of arranging some guest speakers for some of our up coming meetings, and things are looking promising . Well, take care, keep well and God Bless, from Judy Pinchin.

## NEWCASTLE

Hi all, hope everyone is fit and well. Our first meeting for the year will be held on Saturday, 21st April 2018 at Valentine Pool in their function room. It will be great to catch up with our regulars again and also anyone new who would like to attend. I've had several enquiries from newly diagnosed folk so hope to see some new faces at our meetings. These get-togethers are a good opportunity to meet others with CMT as we all have something to contribute. Please don't hesitate to call if you would like to attend a meeting. Kind regards, Gabby Cosgrove

## SOUTH AUSTRALIA

Hello from the CMTAA SA community. I hope everyone had a Great and Safe Easter with their families. An easy and slow start to the New Year for most of us. However not for young member James who on January 7 participated in the Muscular Dystrophy SA 5km Big Red Ride & Run. James walked almost 2.5km and was assisted by his carer to complete the remaining 2.5 km. Well done James! We are pleased to report that we continue to receive calls asking about CMT. Our CMTAA SA Facebook continues to grown to 60 members. A big thank you to our CMTAA president Tony Adams for taking time to catch up for a coffee and chat with our members. Our coffee cups were not yet cold when the CMTAA SA Team were again at it with our first Coffee and Chat for the year at Devour Café, West of Adelaide. After devouring the menu it was great to chat over coffee and participate in an informative chat about the NDIS and other services available or not for the CMT community in SA. Stay tune for our next coffee and chat to be held in the North of Adelaide, 12 May, between 12 -2pm at Café Primo Smithfield. More details on the CMTAA website. Your CMTAA SA Support Group continues to keep CMT information circulated across the SA community. Should anyone require any brochures or posters for personal, community or school feel free to contact us and we well ensure that you receive the informational material. Remember the CMTAA Inc., website has a lot of up to date information about CMT. Finally, thank you to the CMTAA SA Team for their continued support. Remember the Team is spread across the North, South, East and West of Adelaide making it easier for you to chat about CMT, NDIS, concessions, etc. I hope to see as many of you at our May Coffee and Chat. Take Care the CMTAA SA Support Group.xo :)

# NEWS FROM THE REGIONS AND STATES

## BATHURST

In my role as “contact person” for CMTAA in Bathurst NSW, I, with the assistance of my husband Barrie, arranged for a “Coffee and Chat” event for a number of invitees who either had CMT or were connected in some way as a relative or a friend with a sufferer of the disease, Invitees in turn were invited to bring along their own guests if they wanted to. The venue was the McCafe at the local McDonald's. The date was Saturday 3 March. The start up time was 3pm.

I was apprehensive because in fact this was my second coffee and chat happening. The first had been a bit subdued with only one couple turning up. Before arranging this second event, I sought advice from a number of sources and followed through on what I was advised. Still, this wouldn't be a guarantee of success, and I wondered (when turning up at McDonald's at about 2.50pm), “Will anyone turn up?”

Well, I needn't have worried. The advice I had been given was very sound. In fact there were 14 attendees. These included three teenage sufferers of CMT who had attended CMT kids camps: sisters Tiffany and Felicity along with 14 year old Nick. Both young and old interacted socially very well with nobody pausing to think about what to say next.

One thing that stood out to me from the Coffee and Chat was the capriciousness of CMT, with some members of particular CMT-afflicted families having the malady and some not. Within the event itself, it was interesting to note that the two people needing wheelchair (or equivalent) support were the eldest and youngest attendees, myself and Nick respectively. Indeed, Nick and I got on very well and had a conversation which covered many facets of the CMT experience.

It seemed that all the participants were interested in sharing their experiences of life with CMT, either as a sufferer, carer or observer of a loved one. We all agreed that we should have a follow-up event in the near future, but at a different venue than a McCafe. The coffee and cakes were fine, but the noise level was a bit confronting. The Bathurst Visitors Centre has been suggested. Barrie and I will check that out.

Barrie and I were the first to leave at about 5pm. We looked back from outside to see everyone else engrossed in continuing conversations. It'd been a great afternoon.

Sandra Stephens, CMTAA “Contact Person”, Bathurst, NSW 2795

## CANBERRA

The ACT & Region support group met on 22 February. We were very excited to have a guest speaker for the evening and that, no doubt, was the reason for our biggest meeting ever, with 16 attendees.

The speaker was Debbie Douglas, a neurological physiotherapist who assisted me throughout 2017, when spinal pain would not allow me to lie down. I have total confidence in Debbie and was keen for her to share her wisdom with our group.

She began with a summary of the relatively sparse research into exercise for CMT. Although exercise is obviously beneficial, there is still no evidence-based protocol for treatment of CMT.

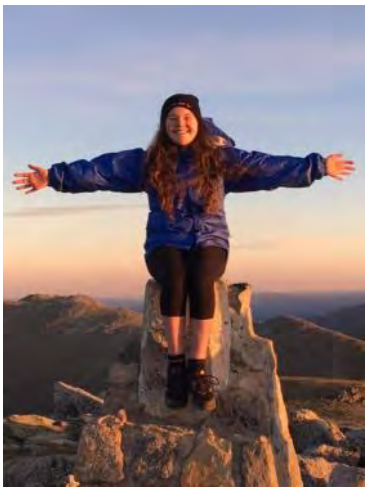
She went on to talk about the essential role that balance plays in coping with CMT. An important point that most of us hadn’t considered is the interaction of sight and hearing with the obvious nerve and muscle feedback required for balance. As our nerve and muscle feedback is failing to some extent, we were all given a timely reminder to take care of our eyes and ears!

Finally, Debbie talked about the impact of fatigue in CMT and the necessity to pace ourselves carefully with any exercise regime. Debbie’s talk prompted a lot of discussion within the group and I’m sure we all resolved to be less sedentary and more active.

Later in the year, I am hoping to have one of Debbie’s colleagues, an orthotist and prosthetist, talk to us about appropriate orthoses for CMT. Gabrielle Evans

# CMT AUSSIE KID CLIMBS MOUNTAINS

14 months ago, CMT Aussie Kid Eleanor underwent major foot surgery on both feet. Like most CMT surgeries her recovery was painful, stressful and long. She spent months in a wheelchair, and more months learning to walk again. Her determination to make the most of her 'new feet' was never more evident than one weekend in January. Whilst we slept early on Saturday morning Eleanor and 5 other Ranger Guides (Senior Girl Guides), along with her 2 magnificent leaders ascended the highest mountain in Australia, Mt Kosciuszko.



**18.6km, over 35,000 steps and something like 7 hours of walking.**

They arrived to watch the sunrise and celebrated their achievement with hot chocolate at the summit. CMTAA is proud to support the CMT Aussie Kids program, which has been running for 7 years. By promoting self-esteem and better self-management in youth, the annual CMT Aussie Kids camps assist in the long term management and understanding of the difficulties and special needs of people with CMT. The camps provide a unique opportunity for the youth to express and work through feelings of frustration, to challenge themselves in a safe and unique environment where all their peers are CMT affected. The youth have established strong bonds through social media and continue to support each other. Stay tuned for more details on the 2019 camp coming soon. Eleanor is a fine example of what you can do when you put your mind to it. CMT doesn't define her! Go Eleanor!

STOP PRESS. Eleanor has recently completed a 25km canoeing expedition on Lake Yarrunga, on the south coast of NSW, and is currently hiking through the Vulcan State Forest over the Easter Weekend.

# CMT: Becoming a CMT Case Manager

At the CMTAA office we often have distressed people newly diagnosed with CMT tell us that Doctors and Allied Health Professionals don't know anything about CMT and they don't know where to turn. I tell them that this experience is common and the terrain can be navigated. After this conversation I often feel that the person is starting a journey from being at the mercy of CMT to one where they own their CMT. It can take time but it owning your CMT does a make a big difference to your experiences of living with CMT. It does not happen overnight, but you will get there. One way of owning your CMT is through how you approach your relationship with the Allied Health Professional treating you. There are no better CMT case managers then you!

To digress a moment about the Allied Health Professionals not knowing anything. This is changing. I put this down to the efforts of our members, their families and the staff of the CMTAA who at every opportunity tell people about CMT for which they all deserve great credit for. Furthermore Allied Health Students (Physiotherapists, Podiatrists, Exercise Physiologists and Occupational therapists) in particular are being told about CMT whilst they are studying. For several years CMT has been used as case study at Sydney University for final year Exercise Physiology students. The students are visited by a group of people with CMT who want to help educate future Allied Health Professionals about CMT. The students are encouraged to ask questions and prescribe a treatment program that will help the person living with CMT. What is great about this exercise is that the people with CMT all have varying symptoms with different life experiences which provides a great learning opportunity for the students.

But anyway, back to being the CMT case manager. To help own your CMT it's a good idea to get an overview of the process that helps to inform Allied Health Professionals about a disease that they are encountering for the first time.

Before the initial interview Allied Health Professionals may be given information which may include a patient's health data such as blood pressure, exercise history, some test results and any known chronic diseases. Common diseases encountered include obesity, heart disease and type 2 diabetes. But what happens when a rare disease such as CMT is encountered?

Google perhaps? Cue fail buzzer. Bad answer! This is going in to the realm of worse case scenarios complete with worse case pictures! Okay, how about something with more credibility, an online medical database describing physical symptoms, potential causes of the disease, medications, how is the disease diagnosed and any evidence based treatments.

From here more evidence based treatment options are searched for, looked at and picked apart. The evidence is in the form of research studies, systematic reviews and case studies. This will often happen before the Allied Health Professional has met a patient face to face. This is important to know from your perspective as providing the Allied Health Professional with as much information as you can about your experiences with CMT and what you want from your treatment is used with the evidence to ensure that you are prescribed the best treatment possible that works for you.

When Allied Health Professionals meet the patient for the first time they may only have time for a short interview. Some of the things Allied Health Professionals are trying to find out include; the symptoms the patient is experiencing, their motivation (why they are seeing you now), their experiences with the disease, what they want to change more than anything else, what's their support is like and what the potential barriers to treatment.

From here the Allied Health Professional then work with you and potentially other Allied Health Professionals to ensure that you are getting the treatment that is best for you. This treatment is based on your goals. For instance what is it you want to achieve by when and how you know you have achieved it? Having clearly defined goals is important as it helps to gauge how you're progressing. This goals based model is used with the NDIS, so it is important for you to have an idea of what goals you want to achieve with your NDIS plan. By you taking a lead role in formulating your goals it helps you feel like you're owning your CMT.

From here you will often need to use your willpower to follow the treatment plan and communicate with the Allied Health Professional about how you are progressing. Don't be frightened of sharing any experiences with pain. What is important is that you are able to communicate with the Allied Health Professional to discern what is treatment pain and what is CMT pain. Also, keep your Allied Health Professional to account by ensuring the treatment plan includes ways of showing progress towards your goal. A good Allied Health Professional will do the same for you. Keep an eye out for this. Do they communicate with you on a regular basis. Also ask yourself if you feel comfortable in asking questions of your Allied Health Professional?

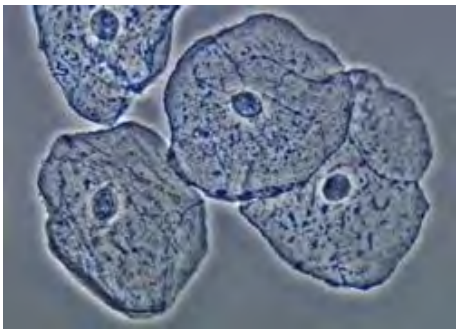
Over time a good Allied Health Professional will develop your self-belief so that you can self-manage your treatment and own your CMT.

So, to recap what you can do to own your CMT treatment by being your own CMT Case Manager:
* Be prepared for any appointments with any test results and other health data.
* Be willing to briefly share your experiences living with CMT.
* Have an idea about what you want from your CMT treatment and be willing to work with your Allied Health Professional to formulate some treatment goals.
* Find an Allied Health Professional who you feel comfortable with communicating about your treatment and keep an eye for how you can hold each other to account.
* Get to know your CMT so you can discern what is CMT pain and what is treatment pain.
* Get involved with CMTAA so you are able to share and help others on their CMT journey. We would love to hear how you get the best out of your relationship with your Allied Health Professional treating you and your CMT.

**By Chris Brown**

***Chris Brown has CMT 1A, he was diagnosed in his mid-teens, had foot surgery on his right foot and is currently in his fourth year Studying Exercise Physiology at Sydney University. He helps out with the day to day running of the CMTAA office one morning a week. For fun(?!) he competes in triathlons, plays touch football and is an accomplished runner.***

# Researchers Grow Healthy, Functional Human Muscle from Stem Cells, New Study Shows



Duke University biomedical engineers created fully functional human muscle from stem cells for the first time, according to a new study. This landmark advancement opens up new avenues for the treatment of conditions related to muscle degeneration, such as Charcot Marie Tooth disease.

The study, "Engineering Human Pluripotent Stem Cells Into a Functional Skeletal Muscle Tissue", appeared in Nature Communications.

Scientists used induced pluripotent stem cells, which can be generated from adult skin or blood cells. The primordial cells are called pluripotent because they can potentially produce any cell or tissue in the body.

The findings add to a 2015 study from the same research team that showed growth of the first working human muscle from cells collected from muscle biopsies. These cells were already beyond the stem cell stage, but were not mature muscle fibers yet.

"Starting with pluripotent stem cells that are not muscle cells, but can become all existing cells in our body, allows us to grow an unlimited number of [muscle-derived] progenitor cells," Nenad Bursac, a professor of biomedical engineering and the study's senior author, said. "These progenitor cells resemble adult muscle stem cells called 'satellite cells' that can theoretically grow an entire muscle starting from a single cell."

Upon stimulation with a molecule called Pax7, the stem cells started transforming into muscle. They first became very similar to adult muscle stem cells, which are intermediate cells before generation of functioning skeletal muscle. Bursac's team was the first to be successful in this last step.

"It's taken years of trial and error, making educated guesses and taking baby steps to finally produce functioning human muscle from pluripotent stem cells," Lingjun Rao, the study's first author, said. "What made the difference are our unique cell culture conditions and 3-D matrix, which allowed cells to grow and develop much faster and longer than the 2-D culture approaches that are more typically used,"

When the muscle generation was at full-speed, the scientists stopped providing Pax7 and created the appropriate support and nourishment conditions the cells needed to fully mature.

The results showed that the new muscle cells form fully functional fibers that contract and react to external stimuli after two to four weeks of culture.

In addition, the newly-generated muscle fibers were implanted into adult mice, where they were able to survive and function for at least three weeks, with progressive integration into the native tissue. However, the new muscle is not as strong as native muscle tissue. The researchers are now attempting to generate more robust muscles.

The stem cell-derived muscle fibers do, however, develop reservoirs of "satellite-like cells," which are required for the repair of healthy muscles. This ability, as well as a far superior generation of muscle cells, are advantages over the 2015 method.

Besides a significant boost in the growth of muscle cells, using stem cells may also enable a series of therapies for muscle-related diseases. It may also help create tailored models of rare muscle diseases, such as CMT and muscle dystrophies, to develop efficient medications.

"The prospect of studying rare diseases is especially exciting for us," Bursac said. "With this technique, we can just take a small sample of non-muscle tissue, like skin or blood, revert the obtained cells to a pluripotent state, and eventually grow an endless amount of functioning muscle fibers to test."

Article originally published by Charcot-Marie-Tooth News. Link to article:
https://charcot-marie-toothnews.com/2018/01/12/researchers-grow-healthy-functional-human-muscle-stem-cells-new-study-shows/

# THOUGHTS?

Someone I met on a dog walk today after talking to me about my condition asked me 'Oh, what a shame, what will you do if your child has it?'

What will I do? And a shame? Now I understand it may have been intended nicely but to be honest it made me defensive. And I hope I came across as nothing more than assertive.

So what will I do?

I will raise him/her to be strong. I will teach strength, I will teach them how to stand their ground, I will teach them how to deal with idiots who question or make fun of their abilities and make them feel small, I will teach them it's OK to come home and cry with anger and frustration after a bad day but then I will teach them how to smile again. I will encourage them to be independent, when they fall over and hurt themselves time and time again (which they will). I will teach them to get back up, brush themselves off and carry on. I will teach them that aches and pains are not to stop them from getting on with life. I will teach them to fight, I will be there through every doctors appointment/ physio/ operations. I will show them they can overcome any obstacle they come across. I will teach them that every day they will come across a struggle they never even knew existed and then I will teach them how to find a way around it. I will teach them to never be afraid to ask for help. I will teach them to pursue whatever dream they have and to not let a 'disability' stand in their way. I will teach them that lifelong condition does not define them but will play a part in the person they become. I will teach them to always be kind and help others, even when the world is not kind to them. I will teach them to know their worth. I will be there through every triumph, struggle, fight and win. I will not however see it as a 'shame'. It is not a shame, it is annoying and it is difficult and frustrating, but it is also what makes me brave, what makes me kind, compassionate and what makes me fight every day. And that is exactly what it will make my children, if they inherit it. I will be that role model who overcame it all and show them they can too. Never be ashamed; It's taken me a long time and I'm still learning but I refuse to be ashamed of who I am.

***This was written by a young woman from the UK, Yasemin Meryem on her Facebook page, and is reprinted here with her kind permission.***

# CMT UK INTERNATIONAL KIDS CAMP

This beautiful design has been created by Jasmin Herro and will be used to adorn the CMT UK Kids Camp hoodies and backpacks when they travel in July this year. Jasmin is a Torres Strait Islander from Mer Island and has kindly donated her time to create something beautiful the kids can take with them to the other side of the world that reflects the journey they are about to take. Jasmin tells the story of Lobaru Promise (Tomorrows Promise) - Miriam Mer Language (from the Mer Island)

'Aboriginal and Torres Strait Islander people for tens of thousands of years used art to remind us how to navigate pathways, build connections and teach us about relationships. Our life takes many twists and turns during this marvellous journey which is depicted by the dots - it is the connections that are important whether it is just next-door or around the world. Our hopes and dreams are carried on thermals of wind, on the crests of waves on the ocean and along the peaks and ridges of the mountains. This journey is never ending and nothing is for certain except the importance of feeling supported as we experience life to its fullest. Sharing a global message of peace, love and respect.'

Jasmin was born in Cairns and is a descendant from the Torres Strait Islands. She has always been entrepreneurial from an early age started selling mandarins from a box out the front of her father's service station to now conducting international business from her suppliers in the worlds manufacturing hub of China and the Asia Pacific to the America's, Canada and the Middle East. She is the CEO and Founder of the multi award winning; Outback Global Australia and Vice President of Outback Global USA. Jasmin was named one of Westpac and AFR's 100 Women of Influence in 2014 and is the winner of the 2014 "Most Outstanding Alumni" award from the prestigious Melbourne Business School.

Jasmin works tirelessly to promote diversity and inclusion around the world and delivered speeches in USA, Canada and China. Jasmin encourages the young and young at heart from all backgrounds to have big dreams and follow them.

Peter and Jillian Critchley from the CMT Aussie Kids are delighted to be working with Jasmin and look forward to their journey to the UK with 9 kids with CMT in July. The kids have been fundraising for over a year now to raise $6000 to travel to the International Kids Camp in Keswick in the Lake District. Everything from High (CM) Teas, Chocolate Drives, Trivia Nights, Sausage Sizzles, Guessing Competitions, Second Hand Stalls and more have enabled the kids to raise awareness and funds for the trip and they are nearly there.

In 2016, the Aussies hosted 5 UK youth and their carers at our Australian camp in Berry NSW. The key to the success of the international camp was the realisation for our youth that people from all over the world are living with this disability. The camp gave new, broader perspectives on dealing with a life of disability and energised the broader CMT community whose only 'complaint' was that they didn't have this opportunity when they were young.

The success of the UK visit has resulted in enthusiastic support for this return visit of Australian youth to the United Kingdom camp in July. In just on 3 months, 11 'CMT Aussie Kids' will travel to London, the Midlands, the Lake District and Edinburgh being joined throughout by members of the UK CMT Community. Supported by the CMTAA, the CMT Aussie Kids program has stretched it's arms out to kids with CMT across the world, showing others that with determination, strength and enthusiasm you can do just about anything with CMT. They are so proud to be taking these kids on a trip of a lifetime. You too can help the kids realise this dream by donating to www.givenow.com.au/cmt

# TASSIE TO HOST 2018 CMTAA NATIONAL SEMINAR

## CMTAA is excited to announce the National CMTAA Seminar will be held in Hobart, Tasmania.

Our CMTAA Committee led by Tasmanian State Coordinator Marilyn Kremmer is assembling a fine group of medical and allied health professionals, along with other exciting speakers who will present at this year's National Seminar.

**SAVE THE DATE:** SATURDAY, 15TH SEPTEMBER 2018

**VENUE:** The Italian Club, 77 Federal Street, North Hobart.

**TIME:** 9:00am—3:00pm (Timings will ensure you can depart Hobart on flights that evening)

**SPEAKERS INCLUDE:** Professor Garth Nicholson, Professor Joshua Burns, Othotist Darren Pereira and a couple of surprise guests.

Morning Tea & Lunch included in the price. Easy parking and access to venue. More details to follow.

**ACCOMMODATION OPTIONS INCLUDE:**

Rydges Hotel, right next door to the North Hobart Football Oval, which is about 10 minutes away from the venue. They have disability access on the ground floor.

12 Manor Rooms (Mix of King & Twin): $143 Per Night Per Room.

23 Superior Rooms (Mix of Twin & King): $152 Per Night Per Room.

# Understanding the NDIS: how does the scheme work and am I eligible for funding?

The National Disability Insurance Scheme (NDIS) has been trialled in selected Australian sites over the past three years. It is now providing funding packages to more than 25,000 Australians under 65 who have a permanent impairment that substantially reduces their intellectual, cognitive, neurological, sensory, physical, psychological and social functioning.

The number receiving the packages is expected to grow to about 460,000 when the scheme becomes fully operational in July 2019. When NDIS participants turn 65, they have the option to stay in the scheme or receive support through aged care services. People who develop impairments from 65 years onwards receive aged care support.

There are 4.3 million Australians aged 16 to 65 with disability and many will not meet the criteria to be eligible for the NDIS. They may still receive assistance through the scheme newly introduced program providing information, linkages and referrals to connect people with disability, their families and carers with community and mainstream supports.

The NDIS will not replace the Disability Support Pension, which provide income support through Centrelink to people aged 16 to 65 who are unable to work because of their disability. The NDIS provides additional funding to meet the special needs of a person with disability, such as to buy a wheelchair or have assistance at home.

**Why do we need the NDIS?**

The NDIS was established in response to a 2011 Productivity Commission report that found disability services were "underfunded, unfair, fragmented and inefficient". The commission recommended a system of flexible individual funding packages that could be used to purchase disability supports.

Before the NDIS, state governments contracted disability service providers to deliver specified services. For instance, some delivered personal care in the home, while others provided day activity centres and other services for people with intellectual disability.

Service provision across different states varied. The person receiving support was usually assigned to one disability service provider and restricted to the supports that agency provided, even when they wanted something different. It was also difficult for people to change service providers.

Disability activists supported the 2011 recommendations for the NDIS scheme and its focus on choice and empowerment to help those with disability meet their goals.

The amount allocated by the NDIS varies across individuals. Some eligible people in trial sites haven't received any funding, such as when their goals were to maintain informal contact with family and friends. By contrast, some received large allocations, including those leaving disability institutions who needed considerable support to live in a five-person group home, a shared flat, or alone with support. The average individual allocation to date is A$39,600.

**How do I know if I'm eligible for the NDIS?**

People with disability, or their family or advocate, can use the NDIS eligibility checklist to see if they are eligible. If so, they can then apply to receive support through the NDIS. If their application is accepted, a planning conversation is held with an NDIS representative about the person's life situation, current supports and hopes for the future.

NDIS funding is available for "reasonable and necessary supports" for people with disability to live a life as "ordinary" as possible. The NDIS website has two useful booklets explaining NDIS eligibility, what it aims to do and how it works. These are: My NDIS Pathway – Your guide to being an NDIS participant; and NDIS Ready — Communications Toolkit.

This includes funding for:

* helping people with personal care such as getting in and out of bed and showering, managing money, house cleaning and other domestic activities

* aids and equipment such as wheelchairs and hearing aids

* psychological, social and speech therapy and physiotherapy

* social participation activities such as in clubs

* transport so people can stay in touch with friends and their community.

Because the NDIS assigns funding to individuals, traditional service provider agencies will lose their government contracts and have to compete in a market environment to attract customers.

Supports can be purchased from any registered disability or mainstream services as long as they are in line with the person's goals. A gym or social club membership can be included in a person's plan.

A formal review meeting is held after 12 months, or earlier if requested, and changes made as required.

Individuals with allocated funding can select a registered service provider to manage and provide their support, or they can self-manage and negotiate the supports specified in their agreed plan, including employing their support workers.

Often family members can do this work on the person's behalf. Only 7% of participants choose to self-manage their funds, while 35% combine self-management and agency management and 58% are fully agency-managed.

**Positives and issues that need fixing**

Early evaluations indicate that people like having the increased control and choice offered by the NDIS. One evaluation found 76% of participants were satisfied with the scheme. People reported improvements in living conditions (71%), health and well-being (60%) and more social, community and civic participation (42%).

Anecdotal reports from trial sites indicate many were initially confused by the changes and needed considerable information and support before they could use the NDIS effectively. The recent introduction of information, linkages and capacity-building (ILC) and local area co-ordinators (LACs) services is designed to address this problem.

But the NDIS has been likened to "a plane that took off before it had been fully built and is being completed while it is in the air".

People with social, cognitive and emotional impairments may find it challenging meeting requirements to apply for the scheme, seek information and negotiate their supports, even with the help provided. The most disadvantaged may miss out, particularly those from low socioeconomic and diverse cultural backgrounds.

Service providers face uncertain futures with governments ending their block funding. They have to compete to attract customers who choose their services. The government has been successful in stimulating competition and the service provider market is still evolving. The NDIS is trying to address these issues. It is early days and the full impact of the scheme is to be determined.

Taken from: https://theconversation.com/understanding-the-ndis-how-does-the-scheme-work-and-am-i-eligible-for-funding-58726

***CMTAA members can contact one of our members,*** *Abbie Moore who has experience in the disability industry and NDIS funding. She is happy to talk to people about how to navigate the NDIS and disability service and support. She can be contacted on mob 0447344499 or email mooreabbie1@gmail.com. Please be mindful that any information is given in good faith. You should consider whether the information is appropriate to your needs, and where appropriate, seek professional advice before making a decision.*

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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 this year, **nine 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

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Young CMTers—CMT Aussie Kids Weekend

**October 2013**

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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
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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
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Personal Trainers and CMT—Gerry Fenyo
Interviews with the CMT Community

September 2010—Seminar, Sydney

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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: 15th July 2018

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)**

**ARB No. 076 189 912**

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