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 89 Winter 2018

CMTAA
Charcot-Marie-Tooth Association Australia Inc.

# The CMT CoMmuniTy

## 30 YEARS OF CMTAA

This year marks the 30th anniversary of the CMTAA. The Charcot-Marie-Tooth Support Group began with a small group of people in early 1988. The group consisted of David Fennel, Elizabeth McDonald, Anycie Berkmann, and Lyla Coorey. Information had been gathered by David Fennell from various sources, including America and Canada. Kay Boreham joined the group in April 1988. Kay recalls : 'We elected ourselves into a working committee with a Chairman to run the meeting and Secretary to take minutes.

Meetings were held approximately bimonthly and usually in someone's home. Each member of the group funded the Support Group through their own personal resources. As more information came to hand, from contacts made by David Fennell and others in the group, we realised that there were many more people in Australia affected by CMT. Research was being done in earnest and some breakthroughs in genetic research were being made. It became more obvious of the need to form some sort of formal organisation.

Discussions then centred on whether to become a member of an international group that had been set up in Canada. Should we become part of another larger organisation with similar, either genetic or neurological, symptoms such as those of CMT? A decision was made that our Support Group would remain independent.

After much deliberation, it was decided that an incorporated association would be the way to go. We had talked to a number of other organisations and looked at how those groups were set up. We had sought legal information from all sources including Legal Aid and various government agencies. The task that was presented to us then was to write up guidelines for a Constitution, one that the Committee felt would best encompass the needs, and possible finances, of a new association and its members.'

(continued page 7)

*(L-r: Kay Boreham, Dr David Ross, Anycie Berkmann, seated Elizabeth McDonald)*

## INSIDE THIS EDITION



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

# PRESIDENTS REPORT

Dear CMT Family

I hope that 2018 has been treating you well. Unfortunately, and inevitably, the complications of CMT mean that some of you will be struggling with your CMT or the impacts of it as I write. Please remember that the CMT Association is here to help in any way we can. Our Coffee Chats are a great way to share a little of your experiences with others who will know exactly what you are going through – this can often be helpful in itself. Keep an eye out on our web page, Facebook page or on Twitter for notices of Coffee Chats near you.

2018 has been a busy year for your committee thus far. Our stand at the Sydney Disability Expo, following a number of years participating at the Adelaide Expo, was a great success. Over the 2 days of the expo we had many hundreds of people stop by to say hi and ask about CMT – including a number of fellow CMT sufferers.

Our CMT Aussie Kids have just returned from their long awaited UK trip to join the UK CMT kids on a camp. All reports are that this was a very successful trip and I would like to thank Jillian and Peter Critchley for all their effort in the organizing, planning and chaperoning on this trip. Our CMT Aussie Kids program would simply not exist but for the tireless work of Jillian and Peter and we owe them a large thank you.

We are very excited that we are able to hold our annual seminar in Hobart this year. We are fortunate that Muscular Dystrophy Tasmania has been able to provide us financial support to ensure that we can bring both Prof Garth Nicholson and Prof Josh Burns to Hobart for this event. Your Tasmanian based committee member Marilyn Kremmer has been working very hard planning for this seminar and hope that as many of you as possible are able to join us on 15 September in Hobart. I am looking forward to meeting with the Tasmanian branch of our CMT family.

Have a great second half of 2018 and be kind to yourselves.

Tony

CMTAA President

# NEWS FROM THE REGIONS AND STATES

## TASMANIA

Once again Tasmania is bracing for winter after having Hobart and areas being hit with devastating floods and wind damage. We were lucky but out thoughts go out to all those affected by this storm. We're busy preparing for the National Seminar in September with the programme and guest speakers all organised. We look forward to welcoming delegates to our beautiful State and suggest they extend their stay and do a spot of sight seeing if they haven't been to Hobart before. We have had a good response from locals with 5 new folk contacting me to go on our Support Group list. We hope to have a Coffee and Chat before the Seminar so that we can welcome them to our group. We suggest folk book early and it would make it easier for folk to pay before attending as with time constraints it may be a bit rushed to get everyone registered and receipts issued on the day. Also registration helps us to know numbers and make catering easier. Don't forget, when booking, to name everyone in your party as name tags will be issued.

Look forward to seeing you in Hobart in September.

Kind regards

Marilyn Kremmer
Tasmanian Co-ordinator.

## ACT AND REGION

The ACT & Region Support Group last met on 17 May. It was another excellent evening, with a good attendance for a cold and blustery evening.

Our guest speaker was Richard Goward, an orthotist/prosthetist and founding partner of Momentum Sports and Rehabilitation in Bruce. He brought with him a selection of orthoses and aids that may be of use in CMT, from basic orthotic inserts for shoes through to top-of-the-line carbon-fibre orthoses designed to improve walking by taking the place of failing muscles. The eye-watering price of the latter drew gasps from the audience! It was good to be reminded that there are so many assistive devices out there, so we shouldn't just keep limping on.

Our next meeting is due in August, generally Canberra's coldest month, so I'm planning an afternoon get-together, in the hopes that we can avoid the evening freeze.

Gabrielle Evans, ACT and Region Coordinator

## GOLD COAST

Hi, Judy here from the Gold Coast. What can I say but roll on Spring, as like many of you I have trouble keeping warm like most CMTers. What a great turnout for our Coffee and Chat morning. Our guest Ernie Tye, gave a wonderful presentation about the Student Clinic being run at the Southern Cross University dealing in all things to do with Medical Grade Footwear, AFOs, Orthotics etc. I'm sure some of them will be going for an assessment by the students fully supervised by the teachers once again. Thank you Ernie. We have a few new members which is good, as some of our members have left due to family and work commitments. Our guest speaker for our next Coffee and Chat morning will give a presentation regarding My Aged Care, packages and Government funding, so I hope people will take advantage of the opportunity to find out more about it.

Well Take care, and Keep Smiling, Judy

# NEWS FROM THE REGIONS AND STATES

## WESTERN AUSTRALIA

Our last formal CMTWA support group meeting was held on a stormy afternoon at the Interface Orthotics premises on Saturday, 26 May 2018. Our presenter was Shanelle Fogarty, Prosthetist & Orthotist at Interface Orthotics who presented to the group a range of latest orthotics that are available on the market including the various options for funding. Thanks to Shanelle for a very informative presentation which was well received by the large group who braved the weather to attend.

**We would also like to announce that Angela Corfe and Chris Murphy have decided to step down as WA state coordinators** after many years of leading the support group. It was Angela and Chris who had the vision to start the group and have been the driving force behind the group for the last 10 years! It all started when Angela received a diagnosis of CMT from Dr Lamont at Royal Perth Hospital after which she contacted the national association who put her in touch with Chris. The association then provided Angela and Chris with a few names of people here in WA……..the beginning of the journey to set-up the CMTWA support group:

- In 2008 our first meeting was at Angela's home in Gooseberry Hill with about six or eight people with partners / family members who attended and found it a great help to touch base.

- The next meeting was at the café at Point Walter which again was very successful and it decided to create a proper group / committee and plan more 'adventurous' meetings.

- Our first major meeting was at the South Perth Leisure Centre in 2009 when Chris arranged the students from Murdoch University to do their presentation about the Graston Technique. At that stage not we asked people for donations to cover the cost of venue hire and had several meetings there before finding our venue at Nedlands provided by the Genetic and Rare Disease Network (GaRDN).

- At this time we also formalised our relationship with the national organization who has supported us ever since.

- To date we have held approximately 25 formal support group meetings with presenters from many disciplines even including some committee and support members.

Thank you so much Angela and Chris for your unrelenting commitment and drive to set-up and run the group over the years. The numerous meetings and interactions have helped so many people from the newly diagnosed to those who have been managing their CMT for quite some time. We will miss Angela and Chris's guidance and energy as state coordinators but also look forward to their membership of the group as we look ahead to many more successful years of CMTWA.

Vic Christou, WA State Coordinator

*Angela Corfe*

# NEWS FROM THE REGIONS AND STATES

## VICTORIA

The Stillness Meditation presentation by Pauline McKinnon was well received and we had a lovely lunch afterwards, it was an opportunity for members to chat and share their CMT stories. An informative and enjoyable afternoon, a thank you to those below that attended.

The Victorian Committee that was formed earlier this year have had a couple of meetings and we are pleased to advise of the following events planned for the remainder of the year.

**12th August** - Information Session from Neuromuscular Orthotics on orthotics and braces developments, NDIS and a chance to meet other Victorian CMT people.

**14th October** – Coffee catch-up. Come along and chat to members and share ideas in a relaxed environment. Venue yet to be confirmed so keep an eye out for emails and updates on facebook.

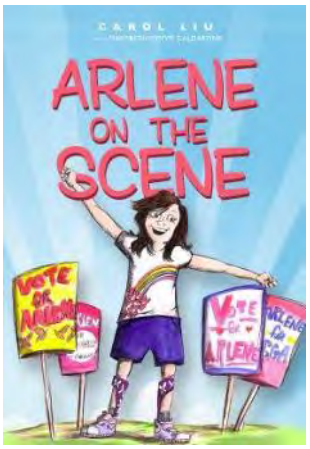
**2nd December** – Inaugural Annual CMTAA Victoria Family Picnic – further information to come closer to the date

As well as email notification, members can also refer to the new CMTAA Victoria face book page, follow us and keep up to date with information and updates on activities. www.facebook.com/cmtaavic www.twitter.com/cmtaavic

A BIG thank you to Kathy, Elizabeth, Maria, Deon and Lesley for volunteering their time and joining the committee. On behalf of the team we look forward to seeing you in the near future.

Warm Regards, Paula Hodgson

# BOOK REVIEWS FROM CMT AUSSIE KIDS



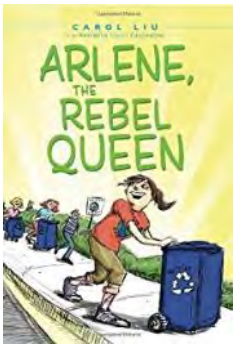

***Arlene on the Scene*** was a great book about someone who has to live with CMT in a school environment. I myself understand going through school life with leg braces was hard and hated how I was treated because of it. Arlene's determination to make her statement that she can do anything anyone else can was very admirable. I felt that the book should of described the inner demons of CMT a bit more but I do understand the importance or inclusive behaviours.

People notice the obvious differences of living with CMT, such as the mobility issues and unsteady gait, which leads to the often standing out difference being our leg braces. However, the subtler and often bigger issues such as our difficulty in getting around crowded environments, our balance issues in this environment and our overall larger personal space out of protection for our feet is our biggest demon that most people don't see. I felt the author although touched on this a few times, they could have elaborated on it further to help others understand the true boundaries of CMT in our day to day activities.

***Fen P, Qld***

Arlene on the scene is one of my new favorite books. I liked that I had lots of things in common with Arlene. This book made me feel like I'm not the only person dealing with CMT. I think it would help any other kids to feel they are not alone.

***Hannah B, WA***




## *Arlene, The Rebel Queen*

Hi, my name is Bryce Hunter from Sydney aged 10 with CMT and I am providing a book review on Arlene the Rebel Queen by Carol Liu. This book is about Arlene in middle school, and the journey and struggles she has with Charcot Marie Tooth disease. When I opened this book I could appreciate the main character and Arlene's struggles in life. I found the journey of reading his book very rewarding with every page I turned. The only difference was the setting was in America and not Australia. I appreciate this book as it made me feel as though I am not the only one struggling with having CMT in this world. It also shows if you have a beautiful family and friends around we can have a wonderful positive life, even with CMT. If you are 10 and struggle at times with CMT I would recommend this book. I mother said it would have been awesome to have this book when she was a child also going through the journey of CMT.

***Bryce H, NSW***

Arlene, The Rebel Queen is a great book that has been written about a girl, who like us has CMT. Arlene has AFOs and her Mum is in a wheelchair. Arlene just gets on with things, but it is difficult to do simple things like getting on the bus and buying normal shoes. Arlene finds out who her real friends are and doesn't want ot be a burden on anybody. At Arlene's school they don't do a lot of recycling and Arlene and her real friends come up with some very funny ways to make the Principal and the students take some action on recycling. Arlene has a strong personality and has to overcome many hurdles like we all do. I liked this book, but the best thing about the book is that it is used in the United States to teach school kids about CMT. How good would that be in Australia?

***Sarah Mc, NSW***

***THANK YOU to our CMTAA President Tony for financially backing this project.***

***4 CMT Aussie Kids were sent a book to review & were asked to give their thoughts in this newsletter.***

***Helping kids and the broader CMT Community share the challenges faced every day and come up with strategies to overcome these challenges.***

# 30 YEARS OF CMTAA

(continued from front page)
When it was decided that the support group should become a registered charity and incorporate in New South Wales, Kay and Conrad Boreham's generosity enabled the group to afford to pay the necessary fees.

The next step was to seek out members for the Association. We needed to find ways to contact people who had been diagnosed with CMT and let them know that a body of information was being collected and could be made available to them. Membership to a CMT Association would have the advantage of a communal voice to the need for information and provision of services.

***Professor Garth Nicholson (l) and June Shepherd***

Approaches were made to Professor Garth Nicholson (Professor, Sydney University, Clinical Sciences Building, Concord Hospital, Concord NSW) who, whilst doing genetic research, had a number of patients with CMT. We printed off invitations and an offer was made by Professor Nicholson to post these out to his mailing list of patients. His assistant, Mary Jenkins, Associate Genetic Counsellor, at Concord Hospital, Concord supported the work of the Association in several ways over a number of years e.g. referring patients to the support group and AGM and information meetings.

In August 1989, our first public meeting was held at Woodstock, a community building in Burwood NSW. Approximately 60 people attended and the Association's first membership forms were circulated. Professor Nicholson was our guest speaker, the first of many guest appearances at the seminars and Awareness Days that have been held over the years.

By June 1990 the Association received its Certificate of Registration as a Charitable Organisation in NSW. Discussions were held regarding our first Newsletter and how we would finance the printing and distribution costs. Our first CMTAA Newsletter was mailed out in October 1990.

***David Fennell, Past President and Founding Member***

David Fennell, an early President had been travelling to various capital cities to locate people in other states that would be able to act as co-coordinators in those states. The membership had broadened to east coast states and the Committee felt the need to have local representation.

Anycie Berkmann continues: 'By 1991 we had a network of three support group contacts in Sydney and one in Melbourne taking CMT enquiries from people with CMT. Over the previous 18 months the Association had made contact with CMT families in all states. Our second Seminar was held in November 1990. Our Volume 2, Summer 1991 edition contained letters from the President of the USA based Charcot-Marie-Tooth Association and from the President of the Canadian CMT Association congratulating us on the formation of CMT Australia.'

The past 30 years has seen much change and development within the organisation. From small beginnings we have grown to represent and advocate for all Australians with CMT. However the one over-riding aim has remained firm: To provide information and support for people with CMT, their Carers, Families, Health Professionals and Friends.

# CMT—OPEN LETTER—ELIZA HULL

Dear You Reading This,

My name is Eliza Hull and I'm a musician. I write songs, sing and play piano. It has been my passion since I was a teenager and something that feels innate to me. I started singing at just five years of age. I've always had a belief that everything happens for a reason; and at the age of five when I started to sing, I also developed a disorder known as Charcot Marie Tooth. Perfect timing perhaps.

So what is Charcot Marie tooth disorder? It is a nerve disorder that stops messages from the nerves reaching my brain. How does it affect me? I walk with a limp, I need a rail to get up stairs, I can't always open lids from jars (it seems to happen more when I'm hungry!). Some of the symptoms can be painful and annoying like last night when I was on a date night in Melbourne and couldn't walk fast enough to catch the last tram. But actually what having Charcot Marie tooth has done for me is more than I'll be able to fit into this letter.

We all have decisions we must make about our lives and how we choose to live them. The way we perceive our lives, and what we create for ourselves, is reliant on our ability to see the good in what we have been given. Over the past year, I have arrived at the most beautiful place. A place of self love. I am thankful for having a disability. I am proud of having a disability. I am now comfortable talking about it and not hiding it. For me, it is about owning who I am. I believe that there needs to be a shift in the way we as a community view people with disabilities. For instance, today when I met someone and they saw me walking they apologised to me and said "oh you poor thing". Whilst I understand that their intention was kindness, it says to me that they consider my life something that ought to be apologised for, which it is not.

The music industry is starting to change. It has been three years since I released any new music and I can feel a difference. Now, there is more talk about diversity; about showcasing all of us: disabled, transgender, all cultures, sexualities, about sharing our stories, varied as they are. People are listening. I remember when I used to meet with prospective agents or managers; I would sit at a cafe table and wait for them to arrive so that I didn't have to walk in front of them. I was afraid. I feared that if they saw me walk I would not get the opportunities I wanted. I was also worried it may go the other way, and I would only be offered the opportunity because of my disability being viewed as a potential marketing tool. I just wanted my music to speak for itself.

But there has been a shift recently. I have come to realise that my identity as a musician is as much about my disability as my curly hair, my love of strawberries and the colour purple. By denying any of it, I would be doing a disservice to myself and to others.

What would I love for the future? More of Dylan Alcott's 'Ability' festivals and others like it, more accessible stages (I've literally been pushed up onstage by my band mates because there are no stairs) and more diverse line-ups at festivals with disabled musicians. But most of all, I would love if people had more conversations about disability, and it's starting to happen. I want us to be visible. I want disabled young people in high school to see disabled musicians up on stage shining brightly, and think 'I can'.

Much love, Eliza x

Eliza Hull's new song 'Hard Way' is out now, listen on Spotify and Apple Music. Like her on Facebook and follow her on Instagram.

*Reprinted with kind permission from Eliza Hull. Taken from Electric Lady's newsletter and website's monthly letter series'*

# SYDNEY DISABILITY EXPO

Our CMTAA President Tony led a team of volunteers representing CMTAA at the recent Disability Expo held at the Sydney Showground at Homebush. It was a great opportunity for the organisation to get out there and network with other like minded people and services, with a lot of emphasis on the NDIS. Thanks to Tony and Angie Adams, Chris Brown, Darryl Beitsch, Peter, Jillian, Matilda and Phyllis Critchley, Kylie, Sarah and Tommy McIntyre and Mike Carroll for flying the flag for CMTAA. Lots of interaction and discussions with members and others helping to spread the word about CMT.


# THANK YOU

Many thanks to the many members of the CMT Community for supporting our CMT Aussie Kids on their trip of a lifetime to the UK to attend the Kids Camp. Your GiveNow or direct donations were much appreciated by all travellers. Check out the story of the trip on page 10 and 11 of this newsletter.

# CMT AUSSIE KIDS UK TRIP

**IN THE KIDS WORDS**

The CMT Aussie Kids Tour of the UK was incredible and it'll be something I will remember for the rest of my life. It isn't often you get to tour another country with friends while also meeting people who understand the struggles of CMT.

The camp was THE highlight for me being able to do things that I haven't been able to do at home, like making it to the top of the rock climbing wall. Seeing others challenge themselves and achieve things they wouldn't have tried was also a highlight. One memory that'll stay with me is seeing one of the boys who had casts on both legs at the top of the rock wall. CMT won't stop any of us. **Steph**

The Lake District was stunningggggggg. I missed home but had such a great time with all my new UK friends and my fellow Australians. **Eliza**

I loved meeting new people who have CMT. The camp was the best ever and I really want to go back again. It was fun travelling with the Aussie Kids and we had so much fun. Jillian and Peter were great and made it easy. I got to see the things I wanted to. Buckingham Palace, ride in the double decker bus and have lunch at Harrods. It was the best. **Sarah**

The further north we went, everywhere I looked there was scenery. The High Tea was great. The sandwiches were BLT but better without the T. They were crisp. **Ewin**

The best thing was being able to become closer and get along more with people whose only similarity with me was CMT. **Eleanor**

We recall **Maddy**'s assertiveness and Australian-ness when she nicely reminded a visitor to the Harrod's Café that (and I quote) 'Oi, lady, the line's back there'. Done with the style and respect we would expect.

Two reflections from **Jillian** during the trip: 'Our last day in camp, and I managed to not completely embarrass myself by balling my eyes out at the end. This group of Aussie Kids sat in a group together on the first night, but by the next morning they had started to mingle. Today I couldn't tell them from the UK Kids and this is exactly why we came. These kids are all keen, motivated and enthusiastic and all with CMT. Peter said in his final speech to the group this morning, that CMT is the one thing we have in common. But he explained we have so much more in common and they are so much more than their disease. They are teenagers, brothers, sisters, sons and daughters who are just trying to get the most out of life, and get through life's challenges unbroken. If this weekend is anything to go by they will do well' AND

'We were happily at Heathrow Airport on our way home, transferred to Terminal 3, through security and were waiting the 4 hours before we departed. The group had the most stressful time in Edinburgh airport, with the cancellation of the flight the night before, resulting in only 3 hours sleep, with numerous hold ups, emptying of bags, juggling passports, boarding passes, questions, being checked in individually rather than as a group, pushing our way through fast track and then being checked again at security. It took us a whole 2 hours to do all of this. We were last on the aircraft and they shut the doors behind us. None of this was our fault and these kids 'smashed it out of the water' as Eleanor would say. All were tired. All have the challenges of CMT and all just took it in their stride. Proud doesn't even start to explain how I felt.'

I had the most amazing time on the trip to the UK! It was so great to meet people who walk just as funny as I do, and be able to share experiences with them. Many laughs were had and many memories were made! **Matilda**

The beautiful scenery of the UK was a background to the extraordinary journey for the CMT Aussie Kids. Keen, motivated and always a pleasure to be with, our youth formed a great team who looked after each-other and who grew closer together as our travels continued. I also remember our British hosts Karin, Paul, Kevin, Nathaniel, Michela and Sophie who went above and beyond to ensure we had the very best time and experienced the very best of the UK. In addition, the support from parents and supporters in Australia and the UK was very humbling. Most of all I look forward to ongoing connections between the Australian and UK Kids Programs . **Peter**

**Well what an absolutely amazing 2 weeks this has been! 9 kids and young adults have just returned from the trip of a lifetime attending the UK CMT Kids Camp in Keswick in the Lake District.** We left Sydney on Thursday morning 5 July, travelling over 24 hours to arrive in a London very early on Friday morning. Our first stop for the first photo opportunity was at Paddington station with Paddington Bear. We dropped off our bags at the hotel and caught the Hop on Hop off bus tour so we could take in the sights of London in a relaxed and sometimes sleepy way, pushing through the jetlag. The next 4 days were spent sightseeing in London and trying to avoid melting in the heat! We did manage to fit in a day to visit Brighton and play on the beach whilst down South, meeting 3 UK Kids who spent the day with us. We broke into smaller interest groups each day, which ensured everyone got to see what they wanted and do what they wanted. The museums, the shopping, the markets, Buckingham Palace....We moved up North a little to enjoy Stratford-upon-Avon, the Black Country Museum and the chocolate in Cadbury World. After a short pitstop for chips and ice-cream and bara brith at Rhos-on-Sea on the North Wales coast and an overnight rest in Chester, we all travelled up to Cumbria for our massive International CMT Kids Camp at Calvert Trust . What a fantastic weekend that was! There were 47 of us; 7 wheelies, 36 wobblies and only 4 walkies and nobody was left out of anything! We swam, canoed, climbed, scrambled ghylls, explored mines, climbed high ropes, sailed down zip wires and many other challenging activities. We had so many laughs and made memories and friends who I am sure will last for many years to come. Karin delighted in hearing the "wow!'s from us Aussies who were discovering the Lake District and Calvert Trust for the first time and when we finally left Calvert, it was with a heavy heart and tired bodies as we moved onto our final destination at Seton Sands near Edinburgh for the last 3 nights. We had visited 3 countries, covering London, the Midlands, the stunning Lake District and played on 3 coastlines during our stay. The trip, journeys and fundraising required to complete all this hasn't been without its challenges, but the overwhelming memories for us will be the smiles, laughter and friendships created.

Along with meeting many CMT UK Kids and their families we were able to meet a few members of the CMTUK Trustees along the way. We had High Tea in Stratford Upon Avon with Mark Edwards, the Chairman and his wife Kate, and were joined by Trustee Richard Batchelor at Covent Garden in London. Trustee and CMT Kids chaperone Sophie Arnold spent all 2 weeks with us, and of course Karin Rodgers our host is another Trustee on the Board. This offered Peter and I valuable opportunities to toss around ideas, and see how others do things. Highly stimulating and engaging. We certainly have lots of food for thought.

One report cannot possibly cover all that happened and can't record every laugh or tear of joy. However Peter and I would like to formally thank the CMTAA Committee for backing our trip. We would particularly like to acknowledge the work done by Anycie, Manju and Chris at the office, along with Robert, our Treasurer with the finances. Their assistance in getting this organised has been invaluable. And of course we would like to thank and acknowledge the UK Team: Karin, Kevin, Paul, Sophie, Nathaniel and Michela. Much of what was achieved cannot be measured, but be assured the kids were amazing ambassadors for both their country and the CMT Community in Australia. We are very proud! What's next???

Jillian and Peter Critchley
CMT Aussie Kids Co-Organisers

# A NOTE FROM OUR FRENCH COUNTERPARTS

Fatigability in CMT is one of the most common complaints from sufferers. Fatigability should not be confused with chronic fatigue. We need a better understanding of these concepts because of the ambiguities you can find in the literature, the meaning being different at times from one language to another.

What differentiates the concepts of fatigue and fatigability?

**FATIGUE:**

Physiological state following prolonged physical or intense mental work with difficulty in continuing. Not to be confused with asthenia (very general, and not entirely muscular, fatigue).

**FATIGABILITY:**

1 Tendency to a greater or lesser extent to tiredness

2 Abnormally rapid diminution of muscular strength following effort.

Neurologists speak of 'effort intolerance'. This state is often associated with muscular disease notably with metabolic diseases with difficulties in using muscle energy. But you find this phenomenon in any other muscular or neuromuscular disease

**CONCLUSION TO IMPART**

* Rest is your friend

* Inactivity is your worst enemy

* Leading to decline & aggravating fatigability

* Activity is your friend when practised 'sensibly'

* Overactivity is your worst enemy

* Find a just equilibrium between necessary & beneficent activity and time to rest

* Research shows the benefits of concentrating effort on the less deficient muscles

* There's no certainty in this but the need to work the still functional muscles is self evident.

* Is there any point in working muscles which have lost their power?...we shall see…

We wish to acknowledge the essential contribution of Dr Olivier Heinzleff and Team at Poissy Hospital.

*REPRINTED BY KIND PERMISSION From French CMTmag110 Winter 2017/2018 p7 Prof Laurent Magy*

*Translated from French by PROFESSOR EDWARD BLACK*

CMTAA
Charcot-Marie-Tooth Association Australia Inc.

# PRESENTS
# The 2018 National CMTAA Seminar

**Saturday, 15th September 2018**
**9am to 3pm.**

**The Italian Club – 77 Federal Street, North Hobart**
which is about 10 minutes from the CBD. Disabled parking and normal parking conveniently available. No steps into the building.

**Registration from 9:00am. Morning Tea available. Speakers start 9.45am.**

**Speakers include:**

**Professor Garth Nicholson,** Neurogeneticist – Update on CMT research
**Professor Joshua Burns**, Professor of Paediatric Neuromuscular Rehabilitation - Management of CMT
**Professor Greg Peterson from the University of Tasmania** who will speak about medication, pain management, drug interaction etc.
**CMT Aussie Kids presentation:** Peter and Jillian Critchley
**Mr. Darren Pereira, Director and Principal** Orthotist of NeuroMuscular Orthotics who will give a talk on the management of children and adults with CMT.
**Mr Hamish Anderson,** Physiotherapist—who will talk about balance.
**Orthotics Display by Neuro Muscular Orthotics of Melbourne – Darren Pereira.**

**Cost- Adults: $25 non members - children under 18 years—$15,**
**Members—$20 -Family $35 where one is a member (eg partner, carer or children)**
**This includes an attendee kit, morning tea and lunch.**

**Please register your attendance and make payment through the Seminar RSVP link at the end of the National Hobart Seminar article on the CMTAA website or by emailing cmtaa2@cmt.org.au or phoning the National Office on 02 9767 5105 by September 10th to register your attendance and pay on the day.**

***If you have any queries, please ring Marilyn (Hobart) on 0409391142 or 62391142 or email mmkremmer1@bigpond.com***

***Registering is essential for catering purposes.***
***Professional Development Certificates available on request.***
***Please notify us if you have any special dietary requirements.***

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# STATE COORDINATORS

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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 2018

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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