

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 90 Summer 2018



CMTAA
Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

CMTAA AND CMT AUSTRALIA

CMT Australia. A new name for CMTAA; uniting all Australians who are impacted by CMT, empowering them to live their lives to the fullest; and encouraging our community to support us.



We all know how much of a mouthful 'Charcot Marie Tooth Association of Australia' can be. Our disease name can be a bit tricky to remember and pronounce. We were finding people who didn't even know we existed, and who were missing out on the many benefits of membership because they simply didn't know where to look. The name has sometimes been difficult to relate to and understand. So the committee decided to do something about it and '**CMT Australia**' was born. We are the same organisation, same support, same resources, same care. Just an alternate name. Our logo and branding will not change. We are not throwing out the old name. It stays. But now we have an alternative to the mouthful of doctor's names, something that recognises our origins in Australia, and gives a nod to the acronym CMT.

You'll find us using the term more and more as we all get used to it. However, be assured that nothing has changed. There is still the same passion to serve our members through support, raise funds for vital research into CMT, disseminate information to our members, and allied and medical health professionals, and provide programs that give kids an opportunity to learn about their CMT.

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

PRESIDENTS REPORT



Dear CMT Family

I want to start by thanking members for re-electing me your President for another year. I believe we have achieved a lot in the last year and look forward to the year ahead. My special thanks must go to Antonia Karydis-Frisan who has stepped down from your committee after many years of valuable service. Antonia has been the backbone of our South Australian presence coordinated many awareness campaigns and fund raisers in South Australia. She will be missed on the committee, particularly for the legal assistance she has provided over the years.

I am very happy to welcome, and congratulate, our two new committee members Chris Meaney as Vice-President and Lisa Moore from Adelaide. It is always great to get some fresh people and ideas into the committee and I am excited for the contribution Lisa and Chris will make over the next year.

As part of my role as your President, I regularly participate in seminars held by Genetic Alliance Australia. Recently we received a presentation about the My Health record, which is, as you would know, currently being rolled out across Australia. While there have been some concerns voiced within the community around privacy I would urge you to review the security, privacy and access controls available for you to set before you decide to stay in or opt out of the system. There are significant controls - driven by you- around who can access your records and what parts of your health record are available. There is also a feature where you can be notified whenever anyone, anywhere, accesses your record so that you can monitor its use. I understand both sides of this debate, but for me I see this as an ideal way for CMTers to further take control of their own health and how it is managed. Because you can see everything on your record you are able to see if any errors exist in notes taken by medical professionals and ask them to correct it. You can also upload your own documents - such as information on CMT, or any other condition, or any factors you would like health professionals to be aware of. I would urge you all to go to myhealthrecord.gov.au and be aware of the facilities available before you make your own personal decision.

We have had a very successful year for donations this year and have been able to assist funding two important research projects. We are however, always looking to fundraise as there is always research to be done! In the world today, with so many good causes, there is much competition for both fundraising and awareness raising. I would appreciate any new ideas for fundraising or awareness campaigns that you might have. It would be great to be able to run a nationwide fundraiser that was able to “stand out from the crowd” All ideas welcome at President@cmt.org.au

I hope you all have a great and safe summer. Be kind to yourselves.

Tony

NEWS FROM THE REGIONS AND STATES

TASMANIA

It's been a busy year organising the CMT Awareness Day in Hobart and it was very gratifying to see the great attendance. Just shows there is a need for disseminating information to folk with CMT. How often do we hear "the Doctor didn't know a lot about it!!" So frustrating. Let's hope more and more doctors become better informed. It was good to see at least 2 medical students at the Awareness Day. Thank you to our Tasmanian Support Group folk for organising the morning tea – what a spread!



Numbers are steadily increasing in Tasmania as more and more folk hear about our Support Group. I aim to have a Christmas Party in December some time and I'll advise folk when I have a date.

In the meantime keep exercising and keeping a positive attitude and be kind to yourselves.

My grateful thanks to the staff at Concord for their help in organising the Seminar. May you all have a safe and Happy Christmas.

Marilyn Kremmer
Tasmanian Coordinator for CMT Australia.
email: mmkremmer1@bigpond.com
or phone 0409391142

GOLD COAST

Hi, hope you are all fit and well and looking forward to Summer? WOW what a year it has been for the CMT family, with the Aussie Kids trip away, the Seminar down in Hobart, plus the AGM and other changes. my congratulations to each and everyone involved, but most of all a big Thank You. The Gold Coast group is going along nicely, with a few new members and a few that have left and moved away. I have started to line up some speakers for next year, so hopefully we can get the word out to more people ! I would like to take this opportunity to wish you all a very healthy, safe Festive Season.

Until next year, Take Care and Keep Smiling, God Bless you all, Judy.

NEWCASTLE

Hi all, I hope you're all fit and well and looking forward to the warmer weather. Our next coffee and chat will be on Saturday, the 24th November. This is our last meeting for 2018 and hope to see our regulars and any newly diagnosed folk who would like to attend. You will be most welcome. Our meetings have been going along nicely and I thought of having a guest speaker attend one of our meetings. Maybe someone to talk about NDIS as this would apply to us CMT folk. More on that later.

I would also like to wish you all a very happy Christmas and a safe New Year.

Kind Regards, Gabby Cosgrove
Newcastle CMT Co-ordinator

NEWS FROM THE REGIONS AND STATES

MELBOURNE

Victoria has had an exciting few months, in August we had the Neuromuscular Orthotics information session with Darren and Paul which was very well attended. September was the National Seminar in Hobart and it was lovely to see a few Victorians there. In October we had a lovely casual coffee catch-up at Brunetti's in Carlton, here we happily chatted for a few hours and indulged in Brunetti's award winning coffee and cakes. We also welcomed two new committee members, Ayda and Elena, it's great to have you join the team ladies.



Upcoming Events:

11th November, 2pm - Our lovely member, Christeen, has volunteered to host a coffee catch up in the South Eastern suburb of Frankston, so please support Christeen and exchange your CMT stories at the **Momentum Cafe, Shop 1/330 Cranbourne Road, Karingal, Frankston**. Christeen was also at the Neuromuscular Orthotics information session and proudly shows off her braces so she is equipped to talk about the benefits of wearing braces. Christeen also loves colour so will be easy to spot, she is pictured on the right with the orange glasses.



2nd December, 11am – 2pm - **The Inaugural Christmas Picnic for Family and Friends**, the details are coming together and we are planning to gather at the Royal Botanic Gardens in Melbourne, please look out for details to be provided in the near future on the CMT Australia website and Facebook page and via email.

Please remember members can also refer to the new CMT 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

Following the picnic your Victoria Committee will be taking time out over December and January to focus their time on their own family and friends, planning will commence again in February, after which we will advise on dates for the activities for 2019, expect more coffee catch ups in Melbourne and Regional areas, information sessions and if the picnic is a hit that will be an annual event.

On behalf of the team we wish our CMT family a wonderful Christmas and we look forward to seeing many of you on the 2nd December for a fun day (with Invictus games!) in the gardens.

Warm Regards, Paula Hodgson

NEWS FROM THE REGIONS AND STATES

CANBERRA AND A.C.T.

For our Canberra mid-winter meeting in August, I thought that a Sunday afternoon might be preferable to the usual evening schedule. But I was wrong! We had the smallest turnout in years, so it seems that weekday evenings are definitely more popular. Despite the small attendance, we enjoyed getting together, as always, and found plenty to talk about. For our educational input I found a presentation from an American orthopaedic surgeon. We all agreed that he gave the best explanation of how and why the foot and ankle deformities of CMT occur, followed by an excellent explanation of the surgical corrections that can be applied. It was obvious that his dedication to his profession is motivated not just by technical expertise, but also by an empathy derived from his own lived experience of a foot deformity. For anyone interested, it can be found at <https://www.youtube.com/watch?v=Tkt1CsBS2Jk&index=5&list=PL7CuX3ETmTf0hix15MfgQp8T5HlzqhrvG&t=0s> Now that we are enjoying the magnificent (though changeable!) weather of Canberra's spring, I hope to see many more attendees at our November get-together. Gabrielle Evans ACT Coordinator

RETIREMENT



It is with regret that we announce the 'retirement' of Antonia Karydis, our hard working South Australian State Coordinator and member of the CMT Australia Committee.

Antonia has been a member of the National Committee since 2006 providing invaluable legal advice and counsel during many CMT Australia activities. These include the Strategic Plan 2017-2020, the establishment of the CMT Aussie Kids Program and the development of the CMT Australia website and South Australian CMTAA Facebook profiles.

She has also been one of the driving forces behind South Australian state Seminars for many years, getting the word out about CMT to Medical and Allied Health Professionals along with the CMT Community. Antonia's enthusiasm for her role saw her lead fundraisers including participating in the 'City to Bay Fun Run' through the streets of Adelaide and 'Grill'd'. She would organise regular Coffee and Chats to support members socially, and was always a strong supporter of all things CMT. The CMT Australia committee would like to formally thank Antonia for her many years of hard work and expertise over the past 12 years and wish her well in her future endeavours.



Let us assist you to meet your mobility, social, recreational & economic goals!



NeuroMuscular Orthotics

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 InterfaceOrthotics  interfaceo

NEWS FROM THE REGIONS AND STATES

SOUTH AUSTRALIA

Spring is upon us, and the winds of change are blowing. October sees changes to the SA support team. Antonia is stepping down from the role of State Coordinator, this role has been taken on by myself, Lisa Moore. Also, Antonia has not renominated for the National Committee Lisa was successful in replacing Antonia on the committee, so South Australia continue to have local representation on the committee.

We take this opportunity to wish Antonia all the best in her future endeavours and hope to continue to see her at some of our gatherings.

“As outgoing State Coordinator, CMTAA committee member and legal advisor I would like to thank the SA CMT Community, family and friends for their support over the years. I have enjoyed meeting and sharing my CMT experiences through a mother’s eyes. I congratulate Lisa on stepping up and taking the responsible positions. I leave you in caring and enthusiastic hands. I would like to take this opportunity to also thank Lisa for her support over the years and wish her and her family the very best. Finally, I would like to thank sincerely the CMTAA Inc., committee who over many years have supported me in my roles and my family. They are an amazing group of people. They should each be congratulated for their tireless efforts over the years for without these dedicated individuals CMT Australia (as now known) would not have been able to continue to successfully operate and reach out and support the Australian CMT community. Thank you.” (Antonia Karydis)

Myself and my son James, travelled to Hobart in September to attend the National Awareness day. Being first trip alone with James, was a daunting exercise. With assistance booked for flights, and the kind sourcing of wheelchair for James to use in Hobart, by MD Tasmania the trip went off smoothly – except for the inclement weather on Saturday. James and Teddy were stars on the planes, and even got to sit in the pilot’s chair when invited into the cockpit when we landed in Hobart. We found the day well attended, all presentations were informative and thought provoking. I particularly enjoyed the session given by Physiotherapist demonstrating so simple stretching exercises. I have sourced the pamphlet collaborated on by Professor Burns and given a copy to James’s therapy team. All have enthusiastically embraced the information and have begun tailoring his therapies to suit. James enjoyed the Aussie Kids presentation and talking with Eleanor about his upcoming surgery. He also found new friends, and had fun playing games up the back all day. I strongly recommend viewing the videos from the day when they become available, as I cannot fully describe the value of the information given on the day. Keep an eye on the CMTAA website for details. If you have the opportunity to attend the national Awareness Day, it is an invaluable day, with lots of information and sharing throughout the day.



Our Facebook numbers continue to grow now sitting at 68 members, with some direct contact seeking us out.

Our August Coffee & Chat included some new members, was a good afternoon greeting some new faces, especially a new little friend for James. A good relaxing time was had by all who attended.

Our final gathering for the year will be on Nov 17. A BBQ at Marshmallow Park Adelaide from 11 -2 pm. Details will be posted on the CMTAA website, SA Facebook group and National Facebook page.

We look forward to seeing all who can attend on the day, to finalise this year’s activities, and formerly thank Antonia and Family.

If any one is interested in becoming a support contact for their local area in SA, please contact Lisa via the contact details listed on the CMTAA website.

All the best,

Lisa Moore & Antonia Karydis-Frisan.

THE PASSING OF A CMTAA LEGEND



DIANA MARGARET DAWES 19 JULY 1930 - 21 AUGUST 2018

Born and educated in Grafton, NSW; trained as a nurse at Royal Prince Alfred Hospital in the late 1940s; trained at Secretarial school and then worked in secretarial roles in various banks; married; moved and started her family in Fiji; returned to Australia in 1972 and settled in Lane Cove; continued to work in various secretarial roles; Rotarian and CMTAA volunteer. All round nice lady.

It was with much sadness that CMTAA has learnt of our dear friend, Margaret Dawes's recent passing.

Current CMT Australia Secretary Anycie Berkmann recalls Marg's commitment to CMTAA with affection: 'Marg as she was known to us worked tirelessly in the CMTAA National office at Concord Hospital first as a committee member in 1997 until 2003 and then as Secretary until her retirement in 2009. She also worked as an office volunteer during this period traveling each week many kilometres back and forth from her home in Northern Sydney. Marg was involved in many aspects of CMTAA work; keeping the office going with assistance from Phyllis Critchley and Stella Weir, answering the numerous enquiries, keeping the membership up to date and assisting with the Newsletter amongst many other duties.

CMTAA and its members owe Marg a very big debt for all her hard work over more than twelve years serving the CMT community. Her wonderful personality, lively wit and efficiency in the office will always be remembered.'

Another former office volunteer and long term supporter of the CMTAA Phyllis Critchley remembers: 'I first met Marg at a meeting of a group of people who had CMT in 1988 when the CMTAA was just starting. When we had the offer to get a small office at Concord Hospital it was Marg and her husband Richard who led other volunteers, working very hard ripping out shelving, rubbish etc so we could have a place to work together.

A few years later we had to vacate that office, but we were offered another room and once again Marg was at the forefront, working hard to get the office as it is today. Marg took over the newsletter editors role, and worked hard to keep it going.

Marg and I worked well together trying to help people with CMT. Marg was a pillar of strength when it seemed the Association would have to close because of a lack of volunteers to cope with the growing membership. She was a dedicated person who wanted to see the association grow with the purpose of helping people with CMT.

Vale Marg. Rest in Peace my friend. Thank you for all you did for CMT'

Margaret is survived by husband Richard, son William and daughters Alison and Stephanie.
Thank you to Marg's daughter Stephanie for providing additional information and the photo for this article.

How support groups can boost your health and make chronic conditions easier to live with

People want to look after their own health, and with new technology, there are more tools than ever to help people manage it. But the greatest gains could come from a little help from your friends.

For people living with chronic health conditions such as arthritis, diabetes and cancer, the health system can seem impersonal and impractical.

A large inhibiting factor to patients feeling involved in their own health care is the outdated medical model that sees the patient as a passive recipient of treatment and advice. The clinical nature of medical care doesn't take enough account of how people live their lives or how they'd like to. The focus is on managing disease, not promoting well-being.

Support from peers – people already living with health conditions – could help fill in the gaps. Instead of just helping combat the disease, peer support groups can help improve quality of life.

Promoting peer-based support from and for people living with chronic health conditions has the potential to improve outcomes, increase access and improve efficiency in health care.

What do peer support groups do?

The internet provides endless access to health information to people seeking more involvement in the management of their own conditions. But finding reliable and relevant sources can be difficult without guidance and support.

Peer-support groups offer advocacy, assistance and education; led and managed by people living with health conditions, for people like them. Traditionally peer support groups are location-based groups that meet regularly, but an increasing number of online groups are expanding access to support.

Peer support groups can offer real, practical advice the medical system is unlikely to bring up. For example, making a cup of tea in the morning to hang on to so the hands can warm up and lose some of the over-night stiffness with arthritis, or how to have a conversation with your boss about a condition they may never have heard of, such as fibromyalgia.

Better disease management

We know wealth affects health – chronic disease prevalence is greater in lower socio-economic populations. We also know health care is heavily influenced by culture, setting and population.

Social interactions have a vital relationship to health outcomes, but medical culture often neglects the importance of social relationships in disease management health and well-being.

The medical model is particularly poor at achieving behaviour change such as diet and exercise. But there's evidence to suggest people who attend "illness-affiliated" peer-support groups better manage their chronic conditions and have better health outcomes than those who solely rely on medical interventions.

(continued next page)

For example, a 2013 study showed improved blood glucose management during peer support group attendance among diabetics.

A recent review also found people who attend illness-affiliated peer-support groups better manage their chronic conditions, with research showing: better health outcomes than those who solely rely on medical interventions; improved access and exposure to additional health services, as well as greater confidence in people approaching or going through treatment; peer-support groups are a cost-effective strategy.

Improving peer support

While all Australian state and territory governments contribute financially in some capacity to peer-support services, there is little consistency between jurisdictions' approaches.

Some state health departments explicitly recognise peer-support services as an essential component of public health strategies and have written policy plans of how to incorporate and build a peer workforce to help organise and lead groups, while others lack a coherent peer support infrastructure. The result is an ad hoc approach with patchy referrals, little quality control and no systemic evaluation.

As chronic disease becomes more prevalent, government and communities should consider a better structure to build upon peer support services to maximise health outcomes. Peer-support has the capacity to provide nuanced assistance and education to those living with chronic health conditions in a compassionate and non-judgemental way.

Government can assist a peer support group for people with arthritis for as little as \$5,000 a year, to allow for things such as venue hire, catering and administration expenses. As the average cost of one knee replacement is between A\$18-\$30,000, it's likely even small changes in how people manage their diseases will provide a return on investment.

From www.shutterstock.com. Authors Ben Harris, Policy Associate, Australian Health Policy Collaboration, Victoria University and Wai-Kwan Chislett, PhD candidate: childhood obesity, Victoria University. Republished under the Creative Commons licence .

We have CMT support groups in:

NSW— Western Sydney; Sydney North; Bathurst; Nambucca Heads; Wollongong & Illawarra; Shoalhaven; Mudgee; Newcastle; Wagga Wagga.

ACT—Canberra & ACT

VICTORIA—Melbourne; Bendigo

TASMANIA—Hobart

SOUTH AUSTRALIA—SA Northern Region

WESTERN AUSTRALIA—Perth

NORTHERN TERRITORY—Darwin

QUEENSLAND— Brisbane; Northern Brisbane; Gold Coast; Sunshine Coast; South-West Area; Townsville

CMT AUSTRALIA NATIONAL SEMINAR

Having put my hand up to hold the CMT National Awareness Day in Hobart I contacted the Muscular Dystrophy Association of Tasmania who were more than helpful in offering financial support . I proceeded to look for a suitable venue which had parking, level access, no stairs, Disabled toilets, AV equipment, kitchen, enough seats and so on!! I finally settled on the Italian Club as it offered all these features.

Next the job of attracting speakers. I was able to get Garth Nicholson, Joshua Burns, Darren Pereira, with the help of the CMT office staff - a local Physiotherapist Hamish Anderson, CMT Aussie Kids, and Greg Peterson.



Tasmanian State Coord. Marilyn Kremmer with CMT Australia President Tony Adams and Prof. Joshua Burns.

I was completely amazed at the response from Tasmanian and mainland folk with over 100 folk turning up on the day. I know Tasmanian folk were desperate for information as this was the first opportunity for them to hear world class speakers. When arranging the Seminar I had opted for the set up of tables and chairs – this proved to be popular as it encouraged folk to speak with their table mates.

As usual we were inspired by the speakers with news of research work from Prof Garth Nicholson, Josh spoke of the developments in the management of CMT, Greg Peterson spoke about drug interactions and the treatment of neuropathic pain, Hamish spoke on the role of physiotherapy in the management of CMT, Darren spoke and demonstrated the advances in orthotic management to facilitate better balance and walking efficiency, Jillian and Peter Critchley spoke of the fantastic program they run for CMT Aussie Kids and we were shown a video of their latest trip to England to meet up with UK CMT Kids. Following the speakers it was time for questions – unfortunately we ran out of time and we were not able to answer all the questions. Tony read out news from Dr Brent Neumann who received a Research grant and a short video was shown where Prof Marina Kennerson spoke about her work which also has attracted a Research Grant from CMTAA.

An amazing morning tea was supplied by the Tasmanian Support Group folk and a lunch of sandwiches and fruit platters supplied by the Italian Club.

It was so heartening to see folk all mingling at the morning tea and lunch break. The response from attendees was very positive and I recommend other States take on the task of organising a Seminar – yes

it was very hard work – especially as we don't actually have a committee in Tasmania – but the satisfaction I got out of it at the end was worth it. I am passionate on finding a cure for this insidious disease as it affects so many of my family and I thank Muscular Dystrophy Tasmania and CMTAA for making this possible.



Tony Adams, CMT Australia President (left), presents Darryl Beitsch with a Distinguished Service Certificate for his many years as the President of the CMTAA and support of the CMT Community in Australia.

BY MARILYN KREMMER



The magnificent turn out at the first ever National CMT Australia Seminar held in Hobart, Tasmania

CMT Aussie Kids Sarah (l) and Eleanor (r) are welcomed by Marilyn Kremmer, Tasmanian Support Group Coordinator and CMT Australia Committee member and Tony Adams, CMT Australia President



From left, CMT Aussie Kids Co-Organiser and CMT Australia Public Officer, Peter Critchley, Marilyn Kremmer, Tasmanian Support Group Coordinator and CMT Australia Committee member, Tony Adams, CMT Australia President, Professor Garth Nicholson, Director Northcott Neuroscience Laboratory ANZAC Research Institute Concord Repatriation Hospital, and Warren Leahy from Muscular Dystrophy Tasmania

From left Rosemary Farrell, Robert Twin, CMT Australia Treasurer, and Darren Pereira, Director/Principal Orthotist at NeuroMuscular Orthotics



A letter from a member



Quick note to thank you,

and especially Marilyn and Dave for a wonderful CMT Conference in Hobart. Mont and I couldn't have been looked after better.

As a bonus, being a born and bred Queenslander we managed to survive the weather which although "slightly" lower temperatures than the Sunshine Coast in Qld neither of us died!!!

The food at the Meeting was excellent and plentiful. The speakers were really informative. I was (and still am) very excited at the developments that are occurring so rapidly in treatment for CMT. Professor Nicholson's information regarding (in collaboration with all parts of the world) a stem cell breakthrough using skin from CMT 1A patients was a big light at the end of a very long tunnel. If he would like some quite old skin (I'm 80 now) I would gladly be a guinea pig!!!

I am waiting impatiently for Professor Josh Burns information on how us CMT people can help ourselves with the correct exercise.; Apparently his paper will be out THIS WEEK!! and my gym people are anxiously awaiting his advice. Also Hamish Anderson from "Back in Motion" gave a great demo on some exercises we can do to help ourselves.

I have 2 brothers with CMT and one has intermittent stabbing pains in his foot when trying to go to sleep. I was REALLY interested in Professor Peterson (BPharm) who gave excellent advice on medicines for just that CMT problem. (Luckily I do not have any pain, and don't take pills of any kind). Last but certainly not least Darren Pereira - Principal Orthotist at NeuroMuscular Orothics gave all us "wobblies" great hope in the department of walking on rough ground, and (joy oh! joy) walking again on the beach!!!! There is great strides being made in all types of Orthoses (including the new field of 3D printers) and I am looking forward to going to Nambour tomorrow to be assessed by one of his colleagues. Nambour is much closer than Brisbane, Sydney or Hobart so fingers closed.

The CMT Aussie Kids gave us a great video of their visit to their English counterparts in London and all over the UK. It was wonderful to see kids just being kids and REALLY enjoying themselves. Any donations towards their next trip would be very much appreciated.

To all who couldn't attend, please try to make it next year. It really is worth your while. I know from the knowledge I keep collecting that my Grandchildren will have a much brighter future thanks to the continuing efforts of our marvellous Committee.

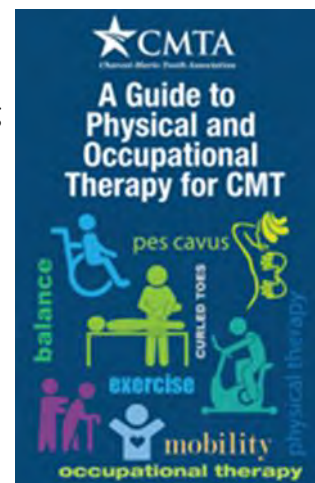
Aileen Harrison
Sunshine Coast Coordinator

CMT NEWS AND VIEWS

NEW CMT PHYSIOTHERAPY AND OCCUPATIONAL THERAPY GUIDELINE

The CMT Assoc of America (CMTA) has recently launched a new and exciting document. Under the leadership of world-class CMT clinicians, including our very own Prof. Joshua Burns from the Children's Hospital at Westmead, the CMTA sponsored a workshop and brought together physical and occupational therapists from the Centres of Excellence to collaborate on a guide to help people with CMT and their therapists better understand and manage their CMT. They have created this comprehensive guide.

This first-of-its-kind publication outlines the assessment and care of people with CMT. As CMT manifests so differently from person to person, this guide, based on research, experience and patient input, will optimize collaboration between physical and/or occupational therapists and patients, helping ensure each individual gets the best possible care for their specific needs.



This invaluable document will empower people with CMT and their health care professionals to safely make educated decisions regarding a rehabilitative plan of action to maintain function and quality of life.

You can download it for free at

<https://www.cmtausa.org/news/a-guide-to-physical-and-occupational-therapy-for-cmt/>

SHOUT OUT FOR OLD NEWSLETTERS

Our CMT Australia Secretary Anycie Berkmann has been looking into making a complete set of all of our national newsletters since Vol 1 and placing them in our archives. She has been able to source most, but is missing the following editions: Vols 25, 26, 27, 28, 30, 31, 33, 61 and 87.

If anyone has a copy they are happy to give to the association either on loan or to keep, we would appreciate it if you could contact Anycie at the office on 02 97675105 Or email: cmtaa2@cmt.org.au.

CONGRATULATIONS to the new CMT Australia 2018/2019 committee elected on 20th October at the AGM at the ANZAC Institute in Concord.

President: Tony Adams (NSW)
Vice President: Chris Meaney (NSW)
Secretary: Anycie Berkmann (NSW)
Treasurer: Robert Twin (ACT)
Committee Members: Jillian Critchley (NSW), Marilyn Kremmer (Tasmania), Lisa Moore (SA)

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NEW ZEALAND

Vacant

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Vacant

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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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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 March 2019

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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