

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 81 Summer 2015/ 16



CMTAA

Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

INTERNATIONAL CMT KIDS CAMP PLANNED FOR AUSTRALIA IN 2016



It is with great excitement that the CMTAA announce that a group of CMT 'kids' from the United Kingdom will be travelling out to Australia next August to join the CMT Aussie Kids at their National camp at Berry.

Karin Rodgers, the CMT Kids Weekend organiser in the UK along with her counterparts in Australia Peter and Jillian Critchley have been in discussions for some time regarding this exciting development. The Critchley's met Karin during a visit to the UK last year and struck up an immediate rapport. The visit should see up to 12 participants from the UK attend the camp and spend over a week touring Sydney and surrounds. The CMT UK association is partially funding this trip of a lifetime for these 'kids'.

One of the volunteers heading down under, Sophie Arnold commented during the recent Skype announcement of the visit: 'I can't wait to meet all of the CMT Kids in Australia and share our stories about how we get on with CMT together'. There are only 2 camps in the world run exclusively for children with CMT; the UK Kids Camp and the CMT Aussie Kids. This visit will further cement and strengthen the ties that bind these 2 groups together.

With nearly 30 Aussie Kids in attendance at this year's camp we are looking at possibly over 40 attendees at next year's camp from the 26-28 August 2016. Only 4 years ago there were just 11 attendees. My how they've grown! Further details: cmtaussiekids@gmail.com



CMT Kids UK

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



PRESIDENTS REPORT with Sue Hardy

Welcome to the Summer 2015 Newsletter.

There has been a lot happening within the Australian CMT world over the past few months.

At the Association Annual General meeting on September 12, I was handed the Presidential baton from Darryl Beitsch. Over the past eight years Darryl has been at the forefront of the CMTAA and I will endeavour to continue to build on the foundations of the past. I would also like to thank the hard working members of the committee for their ongoing commitment and willingness to continue to move the Association forward.

In reflecting on the work the CMTAA undertakes, much happens quietly behind the scenes and I would like to work toward bringing greater awareness of our success not only to members but to the wider community.

Currently the CMTAA focus can be broadly categorised with three headings: Support, Awareness and Research. As you read the articles in this newsletter I ask you to reflect on how you can add your skills and understanding to these areas, helping to build a stronger association.

SUPPORT is the cornerstone of the CMTAA, having evolved initially from a CMT support group. Today support can be found via social media with our CMTAA Facebook page, via our website, support groups around the country, seminars and our very own annual Kids Camp. I urge every member to get involved, even if only in a small way by going along to a support group get-together. Our Kids Camp is vital in the support it provides to kids with CMT but does need some more financial funding as it becomes even bigger and better.

AWARENESS is something very close to my heart. The frustration of not knowing what Charcot-Marie-Tooth Disease is, combined with doctors and allied health professionals knowing even less is very real. Our awareness strategy needs to target the general community, medical practitioners and allied health professionals from podiatrists to physiotherapists. Every member can help here by spreading the word at every opportunity. A photo in the local newspaper about a support group will do as much, if not more, than a national news snippet. It was wonderful to see the September Awareness month taken to heart by so many.

RESEARCH is something we cannot live without. Over the years the money raised by the CMTAA has provided significant grants to allow research into CMT and continues to do so. A quick look on our website will show you what we have achieved to date. I encourage you to put on your collective thinking caps for ideas to raise even more money for research.

As part of the CMTAA it is comforting to know that you are not alone with your CMT. There are many ready and willing to help you along your CMT journey.

Until next time: health & happiness.

Sue Hardy

CMTAA President

NEWS FROM THE REGIONS AND STATES

TASMANIA

Our Tassie Support group met in late August at our home for a get together and debrief after our Focus Group with Scott Denton. We concentrated our afternoon on foot care where a local Podiatrist had kindly lent us some samples of footwear, splints, inserts for shoes and pamphlets on foot care. We also watched the DVD of Josh Burns from last year's Sydney Awareness Day. We always enjoy Josh's presentations. We had a really good turn up (despite snow being forecast again!) and once again a luscious afternoon tea with everyone contributing. Unfortunately one of our group has recently suffered a nasty stroke leaving her paralysed down the right side, affecting speech and swallowing and with CMT complicating her recovery. Talking to the staff they know very little about CMT – even the physiotherapists had little knowledge – making it so frustrating that so little is known about CMT with the medical profession!!

Another of our group has tried to get an appointment with a neurologist and has been told there is a waiting time of 700 days. This is where Support Groups are so necessary for the well being of folk as they can talk to other sufferers and know that they are not alone.

Our Best Wishes to you all – may you have a safe and happy Christmas free of bushfires!

Kind Regards,

Marilyn Kremmer

Tasmanian Coordinator

GOLD COAST

Hi all, Judy here from the Gold Coast, I hope you are all fit and well and enjoying the spring weather. I would like to congratulate everyone involved in the seminar, and by all accounts it went extremely well. I must say that the last meeting was one of the most enjoyable to , as everyone was very relaxed and engaging in the conversation, and we all ended up staying for lunch, our next meeting will be at the end of November, which will be our Christmas get together. I would like to take this opportunity to wish everyone a very Merry Christmas and a healthy, happy and safe New Year.

Take care and keep smiling. Judy

CENTRAL TABLELANDS / BLUE MOUNTAINS SUPPORT GROUP

The NSW Central Tablelands/Blue Mountains support group met up at a café in Hartley for coffee and a chat. The conversations were wide ranging covering everything from shoes to podiatrists and doctors to disability entitlements. These topics were interspersed with much laughter and camaraderie as we sat in a separate room of the old post office built in the 1840s. Originally we had planned to sit outside but the weather decided otherwise on the day.

We started at 1.30pm and at 4.10pm the owner quietly mentioned they closed at 4pm. The time flew by. To get us out she accepted the offer to take a group photo. Funny how the two non-CMT husbands did a quick getaway to avoid being in the photo!

The benefit of simply being able to chat freely and openly with others who understand when you say getting out of bed in the morning is the hardest part of the day or lamenting about not being able to wear a pretty shoe, is of such great value I would encourage everyone to join a local support group or start one if you can't find one. When it came to shoes Rivers got a gold star for their orthopaedic shoes with soft linings and Velcro fastenings.

We will be getting together again in February for another round of laughter. Everyone is welcome to join us. Check the CMTAA website for the date and place. *Photo: Julianne, Racheal, Sue, Joan, Sharon – Pete & Dave hid when the camera came out.*



NEWS FROM THE REGIONS AND STATES

WESTERN AUSTRALIA

The Western Australian CMT Support Group has organised our next regular gathering on Saturday 21 November from 2 pm at our regular venue at 37 Hampden Road, Nedlands.

We have secured Monica Elberink, a remedial masseur with experience with people living with CMT as our guest presenter. This will be our last gathering for 2015 and we look forward to the opportunity to catch up with our regulars as well as having a chance to meet new members of our group.

Our previous meeting was held on 15 August with a presentation from the University of Western Australia Podiatry Clinic who can provide subsidised consultations for our members and custom make shoe inserts and orthotics, using up-to-date technology.

Best wishes on behalf of everyone at the Western Australian CMT Support Group.

Chris

NEWCASTLE

Hi all,

I hope you are all keeping well. Our last meeting was held on the 29th August. We had 2 new people who attended which was great as well as our regulars. It's always good to see new people at our gatherings and share our experiences of what it's like living with CMT.

Our last meeting for the year will be on Saturday the 5th of December. Anyone who would like to attend is most welcome. My contact number is 0412 891 647.

P.S. I had an enquiry from a lady wanting information about the 'ponseti method' (a manipulative technique used to treat club foot.) If you know of anyone who has had this treatment or has more information can you let me know. Thanking you.

Gabby Cosgrove
Newcastle co-ordinator

SOUTH AUSTRALIA

Greetings from the SA CMT team. 2015 has been an amazing year of growth and increased awareness of CMT in SA. Our focus has been to increase our connections with the SA CMT community including their families and friends, carers, specialists, allied health professionals and service providers. The SA team has increased to four whereby we now can provide support north, south, east and west of SA including regional areas. Our hard work and ongoing involvement with the SA community to raise CMT awareness has been extremely rewarding and we hope to continue our efforts in 2016 with the same vigor and passion!

The team have been very busy holding Coffee & Chat quarterly meetings traveling to Murray Bridge, Victor Harbor and Mile End. The highlight of the year was the inaugural SA CMT Awareness Day 19 September 2015 held in the beautiful Adelaide Pavilion function centre, Veale Gardens. Well supported by 45 attendees. Officially launched by the Hon Kelly Vincent, Dignity for Disability Member of the Legislative Council. Our key note speaker Professor Burns amazed and enthused the audience with his latest and greatest news about CMT. The 12 presenters and exhibitors made for an interesting day enjoyed by all and it certainly kept those questions flowing! The day went smoothly and exceeded all expectations. The day not only provided the latest information about CMT but offered management and support suggestions through podiatry, neurophysiology, support groups, NDIS outline for support, SA CMT support group, sourcing aids and modifications for mobility.

Our sincere gratitude goes to MC Isabella Frisan, my SA CMT team Lisa Moore and Andrea Pollock and band of volunteers: Ian Moore, Hoda Teimorzedah, Aisling O'Toole and Janice Phillips and master Fabio Frisan as the all-round helper. We are also very grateful for the generous financial and in kind support of

NEWS FROM THE REGIONS AND STATES

SOUTH AUSTRALIA (continued)

the Directors Georgia and Nick Mavragelos and Dimitrios Loulios of the Adelaide Pavilion, the Julia Farr Ms McLeod Benevolent Fund, client services team at MDASA lead by Amber Pyle, the Douglas family and CMTAA. Speaker gifts: Fiona Davies and Michelle Redhead from Edenmae Estate Wines. Raffle support: Omega Foods, Joanne Deliso, Psorakis Family, Frisan Family and IGA Wattle Park. Without their kind support, we would not have been able to host our awareness day, strengthen our contacts, and develop further networks. Thank you to all.



SA Feedback: Your feedback is important to us. Any suggestions on how we can improve our reach and provide relevant information and activities to assist persons living with CMT is welcomed. We aim to better understand CMT and inform of strategies to improve ones quality of life living with CMT. Awareness day feedback snippets: "Was able to engage with others and share my experiences about CMT and my journey" Anon I really enjoyed your awareness day, and can say after just presenting at the Stanford CMT family awareness day that you all put on a world class event – well done." Professor Burns " I want to congratulate you all for such an informative, well planned seminar on Saturday, we were impressed and grateful to be part of the day" MDASA. "An informative day, learnt so much to help young client with similar symptoms to CMT" Wendy Robertson OT.

SA CMT Membership: SA CMT family is growing 43 contacts 17 are CMTAA members. SA CMT Facebook The closed Facebook group is growing 23 contacts. The team has opted to use one central email address cmtaa-sa@cmt.org.au to contact any of the team. Alliances This necessary work continues gathering momentum. We are working with Carers SA, MDASA, TADSA, Julia Farr and developing leads with RAA, Diabetes SA, Arthritis SA, NOVITA, Royal Adelaide Hospital, Queen Elizabeth Hospital, Repat Hospital and The Women's and Children's Hospital. SA CMT Sessions remaining 28 November - Xmas function at the Findon Hotel all-welcome. We hope to see you all there!

SA 2016 Calendar: Coffee & Chat sessions February, May, August and October. September is International CMT Awareness Month and is set to be a busy month for the SA CMT team with an event proposed for every week in September: 3 September SA CMT Awareness Day, 4 or 25 September BBQ Fundraiser, 10/11 September CMTAA annual seminar NSW (TBC), 18 September City to Bay Fun Run (SA CMT team - TBC), 24 September Ageing and Disability EXPO stand (TBC). There is something for everyone we believe so look out for emails, newsletters, flyers, SA CMT Facebook and CMTAA websites notifications or just call us direct!

As SA CMT coordinator, I would like to thank Andrea and Lisa for their tireless efforts throughout the year and look forward to Simone coming on board. I would especially like to thank Lisa for her graphic and social media work and for the amazing admin support to me throughout the year. Team you have made my job easier and a lot more fun! Thank you. SA CMT Team let's do it all again in 2016!

A Very Merry XMAS to all in CMT land and here is wishing you a great start to the New Year!
Cheers Antonia, Lisa, Andrea and Simone; Your SA CMT Team

A.C.T. COORDINATOR RECEIVES LIFELINE AWARD

Gabrielle Evans, our CMTAA Coordinator for the Australian Capital Territory has recently been awarded Lifeline's 2015 Women of Spirit Award.

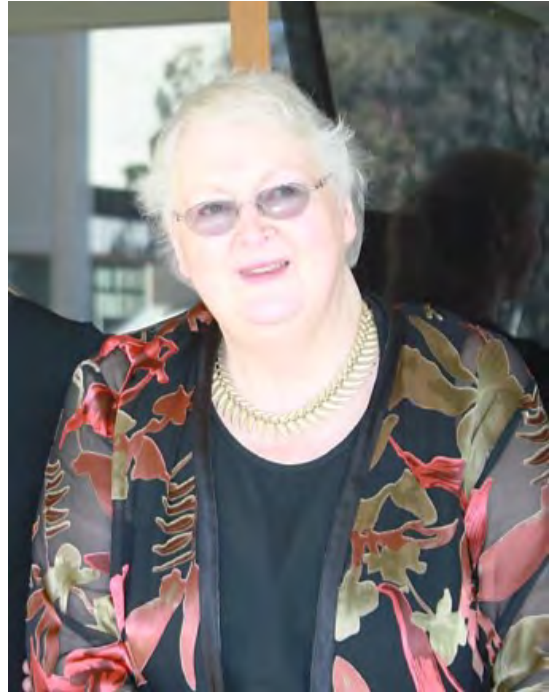
Nominated by her peers, Gabrielle was assessed on the details of her outstanding community work while showing incredible resilience in the face of significant adversity in her life.

Gay Evans has persevered through countless challenges in her life. Overcoming disability, sickness, grief and marriage difficulties, Gay has used her personal struggles and experiences to help others, and has reached countless people in her lifetime.

Surprised by her achievement, Mrs Evans said that while she was delighted to receive the award, there were seven other very worthy nominees who also deserve high-praise for their efforts.

"I am just one of many women in the ACT and region who go about their business, trying to make a difference in society." Mrs Evans thanked her life-long partner John for his unwavering support of her, and the amazing journey they have been on together.

Congratulations Gabrielle on behalf of all of your friends at CMTAA.



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THANK YOU DARRYL

As most of you will be aware Darryl Beitsch stepped down as our President and from the Committee at the recent AGM. This is after 9 years on the Committee, 8 of which as President. Whilst we are all sorry to see his term come to an end we are all very grateful for his contribution to our Association during this period. His achievements are many and go beyond tangible improvements such as the new website. As President, Darryl brought a dynamic 'can do' approach to the Committee that inspired us all to rally to the cause. As a leader of the Committee he invited input from everyone and was the first to give praise and appreciation. He led by example and dedicated countless hours to do the very best that he could in the role. To our general membership Darryl was the face of CMTAA and drove the Association to new heights.

So let us look at the achievements over his term as President. An early goal was to strengthen our financial situation and ensure that our members got the best value for their contributions. Being based in Sydney, Darryl recognised the perception some had of CMTAA as a Sydney centric Association and has worked to build our Regional network and our communication to all members. He embraced the evolving geographic spread of the new Committee and took on the challenge of chairing meetings by teleconference, enabling others to contribute wherever they lived.

Our office procedures have improved dramatically during Darryl's time as President. Our database has been enhanced a number of times and this has been integrated with our new web capability. Both Darryl and Anycie have doubled as office staff and without their contribution in this role we would not have the Association we do today. This is also a good time to mention the important role that Darryl's wife Robyn has played behind the scenes. On many an occasion Robyn has stepped up and contributed when preparing member mail outs and at the Sydney seminars. More recently Darryl has been able to secure two office assistants to take on some of this load, although he continues to come in once a week to ensure all runs smoothly.

For those who have attended our Sydney seminars during the past 8 years you will have seen the many enhancement in the quality of the speakers; the response to your feedback; the improvement in the venue; and the extension to include the AGM and informal gathering on the Saturday. Darryl has been the driver for many of these improvements as well as managing the seminar program and being MC. This success is now being picked up by other regions, offering greater opportunity of our membership across Australia to become involved. The move to release the video of these events on-line also expands our service to our members.

Although it is hard to promote one achievement over so many, Darryl's vision to enhance our web presence does stand out as a beacon of success. This was much more than a simple switch of provider. It involved a new branding of CMTAA (logo), a significant improvement of our member support, and projection of the Association within and beyond our shores. We now have a modern and efficient website with online payment capability and links to all our resources and those of like associations. CMTAA is now internationally recognised as a leader in the support of those with CMT. Darryl has also contributed to this status through trips he has made to international meetings, and networks he has joined, particularly in the UK.

Darryl quickly recognised the potential of Youth Weekends, an idea put forward by Peter and Jillian Critchley. These have undoubtedly been a roaring success and next years will be bigger than even. Other initiatives during his term as President have been our presence on Facebook; our Sustaining Partner program; the Constitution upgrade; enhanced approach to managing our research grants; and support for the Department of Health grant and the recently completed report by Dr. Scott Denton.

It is difficult to summarise our achievements during Darryl's term as President in just a few paragraphs. He will be the first to acknowledge that these have occurred with input from others; however every team needs a leader and we have been very fortunate that Darryl accepted this challenge back in 2007. Your Association was very pleased to have been able to thank both Darryl and Robyn for their support and contributions to the CMT family over such a long period during our recent Sydney Seminar. Whilst stepping down as President, Darryl will remain behind the scenes to provide website and office support.

Thank you Darryl and Robyn, on behalf of all CMTAA members.



CMT AUSSIE KIDS WEEKEND 2015

We asked our CMT Aussie Kids to reflect on what the camp has given them. This year marked the fourth year we have celebrated everything CMT Aussie Kids and next year brings with it the excitement of a visit from our UK CMT friends. Here are some of the comments from the kids after this year's camp. Some of them will make you smile, and maybe some will make you cry (well they did for me—Ed) ENJOY!

This year was my second year at camp. I found it so easy to settle-in and get to know everyone last year. This year it was even easier as I knew most of the people. Since I went to camp last year I don't feel isolated about CMT, like I did before. If I'm having a day where everything hurts for no reason I can message or call some people who feel the same. I don't feel as shy about CMT or myself either, I'm helping to try and organise a CMT awareness day at school some-time during September. In the last year I believe I have changed a lot, I was a loud person before but I now have confidence to go with it. I don't care as much about what people say to me about CMT. I know people who understand. Originally camp was out of my comfort zone and I was extremely nervous last year. After everyone else arrived everyone came and introduced themselves and it was amazing. I was instantly welcomed into the group by the original campers. The CMT Aussie Kids weekend is an experience I'll never forget: everyone has become a second family to me now, and we help each other out where it's possible no matter where we live in the country.

CMT Aussie Kids became more than the group of friends that were there when we all first arrived on the weekend. I've gotten a lot of confidence and I don't feel like a freak anymore especially when I'm just going through day to day stuff.

The CMT camp has changed dramatically about the way I think about myself, I felt happy because I was not the odd one out, I was NORMAL. Attending the camp has helped me feel better about my abnormal feet because some people there haven't even had the treatment that was available to me such as night and day splints and serial casting on my feet. The reason why it has affected me is because I felt lonely, abnormal and most of all the weird one for the past 11 years of my CMT journey. There was really only one reason why I didn't want to come to camp which was I wouldn't make any friends because I don't really make many friends at all due to my disability and problems, but the people here were very friendly. After being to the camp I felt like my CMT isn't a disease that is 1 in a million, from what I know it is about 30% of the world's population. (Ed: 1 in 2,500) The CMT camp was great for me and my brother and I hope each year more and more people are able to attend this uplifting camp.

I love going to CMT camp because I meet new people and everyone around me has CMT and that makes me feel more confident. It doesn't matter if you fall over and you have funny feet. It is just so much fun.

If you have CMT you can do so many things and you can do everything that everyone else does. I was really excited at my first camp and I wished I could have gone earlier but I was too young.

I have so much fun meeting up with all the kids because they are all different ages and come from all over Australia.

I go back to my school and do a presentation to my class and tell them all about the camp and CMT, particularly because September is CMT awareness month. My friends know why I fall over a bit and why I am a bit clumsy, but they love me because I'm me!!!

I really look forward to the CMT camp every year and the fun we have; my brother can't wait to go when he gets bigger.

2015 was my first year of attending the camp, I was invited in 2014 but being newly diagnosed I didn't want to go. Before I went to camp, I used to shrug off CMT and didn't want to talk about it. I changed my mind about going to camp in 2015 when I was strongly encouraged by my Mum and another camp attendee. At the camp I had the opportunity to talk with the others about CMT but there was no obligation and I liked that there was no pressure to talk if I didn't want to. I thoroughly enjoyed the camp, I was shocked how nice everyone was at the camp (they were really really nice). The activities at the camp were good and everyone got to have a go. I feel since going to the camp, I have more knowledge about CMT. I now feel more confident in answering questions from people if they ask me anything about CMT. I have made numerous new friends at the camp and we still talk now camp is over. I look forward to having the opportunity to attend again next year!

The camp changed the way I see life, and CMT. Being able to spend a weekend with a bunch of people I felt 'normal' around has really helped, because honestly some people just don't get it. This camp has allowed me to make many new friends, and through the years make them stronger and worthwhile. The friends I have made I know will be life friends and may be the future of CMT Aussie Kids. The camp has lifted my own well-being both social and emotional well-being. I have enjoyed the 4 years I have attended and will definitely be back next year!

See more action from the camp on YouTube <https://www.youtube.com/watch?v=djdi603LrmU>



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Position vacant

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NEW ZEALAND

Position vacant

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TASMANIA

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NORTHERN TERRITORY

Darwin

Mrs. Kaye Bartlett (See above)

NEW ZEALAND

Vacant

THANK YOU for donations from 16th July 2015—30th October 2015

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R—Donation to research

A— Donation to administration

Y—Donation to CMT Aussie Kids Youth Activities

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

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

YOU CAN ALSO DONATE ON OUR WEBSITE

<https://www.cmt.org.au/control/donate>

HOW YOU CAN HELP THOSE WITH CMT

Your Association has 5 key objectives which can be summaries as follows:

Obtain and distribute information related to the welfare of people with CMT;

Provide assistance and support to these people and their families;

Promote the development of support facilities and services for this group;

Increase community awareness of CMT and those who suffer from this disease; and

To support research into CMT.

To fulfil these we produce a newsletter 3 times a year; support a comprehensive website; have a presence on Facebook; and conduct seminars and informal get-togethers across our regional network. We also conduct our Youth camp each year; produce promotional leaflets; promote CMT awareness to governments, medical professionals and allied groups; and we distribute grant funds according to a structured call for expressions of interest and Committee review. These services are delivered almost exclusively by volunteers in the most efficient way that we can.

Our volunteers represent a very small group within our membership and are generally on our national committee or form our growing regional network of Coordinators and their sub-committees. Whilst our active supporters are critical to our success, they would not be able to carry out this work without the funds that we are able to attract, mostly from you our members.

We are seeking your help to enhance what we currently do and to extend this into other ways to meet our common goals through donations. Recently we have improved the payment options for our donors and we now have 3 ways in which you can support your CMTAA. Remember that we are registered as a Deductible Gift Recipient (DGR) and therefore all donations over \$2.00 are tax deductible and we will provide you with a receipt.

We accept donations by cheque posted to our office at Concord Hospital (Building 22, Concord Hospital Concord NSW);

You can directly deposit a donation into our account at Westpac (BSB 032-069 Acct. No. 158486 Acct. Name: Charcot-Marie-Tooth Association of Australia Inc.); or

You can donate online by credit card or PayPal through our website at www.cmt.org.au (<https://www.cmt.org.au/control/donate>). We don't receive any card details as this is all handled by PayPal.

If our small team of volunteers can harness your support through increasing our donations then all of those/us with CMT will benefit. The web link above is the best way to advise us of your donation. Please enter the total amount in the first entry box and then if you wish you can distribute your donation across our 3 options of Research, Administration and Youth Activities. There is a 4th box for a donation on behalf of a particular person where they are participating in a special fundraising event on our behalf. Enter the rest of the details if not pre-populated and then select your payment option. Don't forget to hit the SUBMIT button.

If you use your personal member login before opening the donation web page then all your details will be pre-populated, simplifying the process even further. The email address we hold for you is your username and only you know your password. If you have forgotten your password there is an option in the login box in the top right to reset this.

It is as simple as that. Make the most of the contribution others are making on behalf of all CMT sufferers and donate today.

Thanks in advance

Robert Twin

CMTAA COMMITTEE (2015/2016)

Executive Members

President:	Sue Hardy (NSW)
Vice President:	Katherine Robins (VIC)
Treasurer:	Robert Twin (ACT)
Secretary:	Anycie Berkmann (NSW)

Ordinary Committee Members

Newsletter Editor/ CMT Aussie Kids Co-Organiser:
Jillian Critchley (NSW)

Legal Advisor: Antonia Karydis (SA)

Joanne Liso (NSW)

SEMINAR DVD's & VIDEOTAPES

October 2014

Prof Garth Nicholson—CMT Research and Achievements
Prof Joshua Burns—Developments in the Management of CMT

Dr Andrew Wines—The surgical management of the foot and ankle in CMT patients

Lyndal Douglas—Genetic Counselling

Lois Tonkin—Principles of Pain Management

Judy Gates, Gavin Fernandes, Leanne Huxley—Posture and Balance Workshop

Young CMTers—CMT Aussie Kids Weekend

October 2013

Prof Garth Nicholson—CMT Research Achievements.
Assoc Prof Joshua Burns—Developments in the management of CMT

Dr Alison Shield—General Principles Regarding Medication and CMT

Rebecca Howard, Senior Occupational Therapist, Independent Living Centre—Technology to Improve CMT Quality of Life

Breakout Sessions

Interviews with people with CMT.

A panel of speakers with CMT Q & A

September 2012

CMT Research Achievements—Prof Garth Nicholson
Dev'ts in the Management of CMT—Assoc Prof Joshua Burns

Clinical Psychologist— Helga Hemberger

Physiotherapy in prep for appropriate exercise—Dr Kristy Rose

CMT and Sport—Dr Che Fornusek

Presentation from Inaugural CMT Aussie Kids Weekend

Interviews with the CMT Community

CMTAA research recipient presentation

September 2011

CMT Research Achievements —Prof Garth Nicholson

Dev'ts in the Management of CMT—Assoc Prof Joshua Burns

PGD in IVF— Dr Don Leigh

The role of the Podiatrist—Karl—Heinz Schott

Personal Trainers and CMT—Gerry Fenyo

Interviews with the CMT Community

September 2010—Seminar, Sydney

CMT Research Achievements —Professor Garth Nicholson

An International Research Perspective—Dr Joshua Burns

Successful Podiatry for people with CMT—Ms. Anita Hood

Appropriate footwear for CMT sufferers—Mr Casper Ozinga

Success stories from children and adults with CMT

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

All contributions, letters, and enquiries should be directed to the Editor, CMT CoMmuniTy newsletter, 15 Naranga Avenue, Engadine 2233 N.S.W. or email: cmtaa@email.cs.nsw.gov.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 March 2016

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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

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

KEEP IN TOUCH

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

Address: _____

State: _____

Postcode: _____ Phone: () _____

Email: _____

Signature: _____ Date: _____

NEW MEMBERSHIP

☐ (\$40.00 per year) \$ _____

RENEW MEMBERSHIP

☐ (\$40.00 per year) \$ _____

DONATION TO RESEARCH \$ _____

DONATION TO NAT.ADMIN. \$ _____

DONATION OTHER \$ _____

Donations \$2.00 and over are Tax Deductible.

☐ DVD OF SEMINARS
(\$25.00 each incl postage) \$ _____

Year of Seminar _____

☐ DVD hand exercises
(\$15.00 each incl postage) \$ _____

TOTAL \$ _____

Pay online at www.cmt.org.au

OR Electronic Funds Transfer: Our bank details are:
BSB: 032-069 Account number: 158486. Please indicate the code/s below that your payment has been allocated to, along with your surname for the transaction information.
M—Membership
R—Donation to research
A—Donation to administration
Y—Donation to CMT Aussie Kids Youth Activities

OR By Cheque made payable to :Charcot-Marie-Tooth Association of Australia Inc. and post to: CMTAA Bldg 22, Concord Hospital, Concord NSW 2139

Charcot-Marie-Tooth Association of Australia Inc.

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

ARB No. 076 189 912

ABN No. 63076 189 912

Donations \$2.00 and over are tax deductible (DRG No. 018352).

PLEASE NOTE: WHEN PAYING YOUR MEMBERSHIP RENEWALS BY ELECTRONIC FUNDS TRANSFER (EFT) REMEMBER TO MAIL YOUR MEMBERSHIP RENEWAL FORM TO CMTAA SO WE CAN ENSURE YOUR DETAILS ARE CORRECT AND UP TO DATE AND WE KNOW FROM WHOM THE PAYMENT HAS COME. IT WILL ALSO HELP US TO ACCURATELY ALLOCATE DONATIONS AND ANY EXTRA PAYMENTS MADE. IF YOU INCLUDE YOUR MEMBERSHIP NUMBER IN THE EFT TRANSFER DETAILS WE WILL FIND IT EASIER TO RECORD YOUR PAYMENT. IF PAYING BY CHEQUE, PLEASE ENSURE YOUR NAME & MEMBERSHIP NUMBER IS WRITTEN ON THE BACK OF THE CHEQUE .



International Awareness for Charcot-Marie-Tooth disease

Find out more at
www.cmt.org.au



CMTAA

Charcot-Marie-Tooth Association Australia Inc.

If undelivered please return to sender at:
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