

The newsletter of the Charcot-Marie-Tooth Association of Australia Incorporated, providing information and support for people with Charcot-Marie-Tooth disease and their carers, health professionals and friends.

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CMTAA

Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

FIRST EVER INTERNATIONAL CMT KIDS CAMP

HELD IN AUSTRALIA

The CMT Aussie Kids camp is a project of the CMTAA who have been proud supporters of this National CMT camp for many years. This year a group of 10 kids and adults with CMT visited us from the UK to attend the CMT Aussie Kids camp and explore Sydney and it's environs. It was, at least for us, one of the most satisfying things we have ever done. Celebrating new (and old) friendships, learning from each other, and just being together. CMT Aussie and UK kids united as one. The camp saw everyone canoeing, rock climbing, doing archery and going down the Cable Glide, the longest in the southern hemisphere.

The Aussie Kids welcomed their UK counterparts with open arms, as if they'd been mates all their lives. They just clicked and have now established new social media links and support groups because of the camp. We were pretty proud of our Aussie Kids.



The community support was amazing too. Outside of the camp the UK kids enjoyed visits to Manly Beach with Mike Carroll organising a brilliant day of surf and education, with lifesavers included, and a wonderful lunch sponsored by our CMT community; an Indigenous performance by friends of Peter's from the Ngemba clan; a tour of the Illawarra and another of the Blue Mountains; a Tall Ships Cruise on Sydney Harbour; lunch at the Australian Heritage Hotel; a trip to the local Astronomy Club to view the southern hemisphere's stars (which was a bit tricky with the cloud cover); a Bridge Climb of the Sydney Harbour Bridge and a good old Aussie BBQ. There were many tears as we farewelled them at the airport after spending nearly 2 weeks with us.

And do you know what we learnt? We learnt that even though you have CMT you are never alone. There are other people going through the same trials as you. There will always be someone who understands and who can listen when you're just a bit fed up. Even if they live 17,000km away...they will understand. We learnt to give it a go. You might just be surprised. Thank you to our supporters, many of which are members of CMTAA. We know, with your help, we are making a difference to the lives of kids with CMT. *Peter and Jillian*

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PRESIDENTS REPORT



Dear valued members of the CMTAA Family,

It with great honour and pleasure that I write to you all as the new President of the CMTAA. Since my appointment as President back in August, things have been moving very quickly which has been wonderful to see.

I would like to take this opportunity to congratulate all of the re-elected and newly elected members of the Committee: Secretary Anycie Berkmann from NSW, Antonia Karydis from South Australia, Vice President Rebecca Poyner from VIC, Jillian Critchley from NSW, Marilyn Kremmer from TAS, Treasurer Robert Twin from ACT and myself from QLD.

This wonderful team of dedicated and hard working individuals have made it their mission to help the Association grow and to help support all of our amazing members. I would also like to knowledge all of our State Coordinators and Support Group Coordinators. Everyone has an important part to play, and together, we all shape the bright future of the Association.

In recent weeks, many of us gathered in Sydney for a very important Strategic Planning day. On this day, we all discussed how we can help support our members even better, how to raise more awareness and funds for research, how to get the community involved and many other exciting things. Lots of wonderful ideas came from the day but the most important thing that we all walked away with, was a mission. We have so much to work towards, so many plans to put into action and so much to cover all of our amazing members that it really is a wonderful time to be a part of this sensational National Organisation.

We look to the future with passion, drive and a deep desire to bring even more hope and support to our members.

I would like to thank each and every member for their continued support. The Association wouldn't be what it is today and we wouldn't be where we are if not for the support from its members. I look forward to the future ahead where I hope to be able to meet most, if not all of you. Rest assured that as members, you have the best team possible working hard towards exciting things as we look forward to sharing the journey with you all.

Christmas Message from your President

I would like to wish you all a very Merry Christmas and a Happy New Year.

Thank you everyone for all of your amazing support through out 2016. Thank you for attending our support group meetings, our seminars, for participating in our CMTAA Awareness Month Challenge, for your donations and much much more. We are so grateful for each and every one of you and we are so happy to have you as part of our CMTAA Family.

2017 is bringing new and exciting things. You will be seeing much more of us and we cannot wait to bring you along on the journey with us.

My wish for you all over the Christmas period is to be safe, and be merry. Whether 2016 has been good, bad or both, you made it through. CMT can really knock us down and about, it can take us to places we wish we didn't have to go, it can push us to our limits and really drain us down to our core....but you all made it through! There would have been times through the year where you pushed beyond your limits, where you kept going when most would have given up. You are all amazing. You all have such strength and determination and I want each of you to take a moment before the year is over and reflect upon how truly wonderful you all are.

May 2017 be exactly what you hope it to be and I wish for you all good health and prosperity. Enjoy the festivities and end of year celebrations. Have a very Merry Christmas everyone and a happy New Year.

President Nelly Sutjipto



NEWS FROM THE REGIONS AND STATES

TASMANIA

Feeling inspired after an amazing day with the CMTAA team for a Strategic Planning Session in Sydney. I feel privileged to be part of this team and look forward to the future in the hope of seeing cures and treatments for folk with CMT. Listening to Garth Nicholson, Josh Burns, Scott Denton and Committee members with their positive outlook with great ideas to bring CMT more into the public eye made me want to get out there and recruit more members! We need money for Research and the more members that join help us attain these goals. I encourage all folk with CMT and their families to become financial members and perhaps even make a donation on the CMTAA website. Next year I hope to hold an awareness day and would appreciate any help from interested folk."



Marilyn Kremmer, Tasmanian Co-ordinator.

GOLD COAST

Hi, Judy here with greetings from the Gold Coast. Hope you are all fit and well, and enjoying the warmer weather. As it is coming up to that time of the year again, I would like to wish you all a very Merry Christmas and a Happy and Healthy New Year. The Gold Coast Gang's Christmas lunch will be held at Club Southport - (C.S.I), Scarborough St, Southport on Monday, 28th November, at 11.o'clock, R.S.V.P by the 20th November Ph 55638421 The Support Group is going along nicely, and I feel that people are enjoying having a chat with other members of the C.M.T family, followed by lunch, which I feel the social aspect plays a big part. I am now going to the Neuromuscular and associated allied clinics at the new Gold Coast Hospital, and I cannot fault any thing, and it is surprising how well known C.M.T is becoming to them, so it can only mean the word is slowly getting out. Until next time, take care and keep smiling. **Judy.**

NEWCASTLE

I have arranged a meeting for our Newcastle members (and anyone else who would like to attend) on Saturday the 26th November at Valentine Pool in their function room. This will be our last meeting for the year so hope to see you there. This is a good opportunity to meet others with CMT as we all have something to contribute and learn from each other.

Please phone me on 0412 891 647 if you would like to attend or would like more information.

Gabby Cosgrove Newcastle Co-ordinator

VICTORIA

Victorian CMT Meet Up Sunday 13th November Time: 2.30pm Where: The Boatbuilders Yard - 23 South Wharf Promenade, South Wharf RSVP: 6th November to Paula via email - paula_denise@bigpond.com or text – 0419351765 NB: The venue is wheelchair friendly, please advise if you do use a wheelchair so the venue can ensure we have sufficient space. Parking: DFO car park at South Wharf - 50% discount vouchers available from the Boatbuilders, remember to ask for the voucher on the day.

Alternatively, the venue is also accessible by train and tram, please refer to the website for more information <http://www.theboatbuildersyard.com.au> The Boatbuilders Yard is an award winning bar and cafe conveniently located on the edge of the CBD at South Wharf in a relaxing oasis of parkland and trees next to the Yarra river. Your CMTAA committee has been busy and Rebecca, the new Vice President, will be joining us to chat about the activities planned for the Association. It is an exciting time as we are on the cusp of some great initiatives, so please join us in this relaxed environment to meet and chat to CMTAA members, family and friends.

Warm Regards, Paula & Bec

NEWS FROM THE REGIONS AND STATES

SOUTH AUSTRALIA

Greetings from SA! Your SA CMT Team have been busy this year raising CMT awareness across the SA community in many interesting ways. From interviews on the Coast FM airways, taking the Team out to 4 quarterly Coffee and Chats in the north, south, east and west, holding the 2nd SA CMT awareness day, participating in the annual Disability and Lifestyle expo, attending peer group support sessions, networking and building alliances, entering in Sunday Mail fun run, holding a fitness session in the Park, various social media posts and various print media (SA CMT News December out soon). The Team continue to do their best in providing connections, sharing information and supporting those living with CMT including their families and carers, allied health professionals and medical experts. The Team strive to think of new ways to provide their support and look forward to hearing from the SA CMT community for their feedback and any suggestions. Looking back at the past twelve months it has been very busy and extremely rewarding in that we have truly made an impact upon increasing CMT awareness across the SA Community. The Team made the most of September being CMT International Awareness month and look forward to doing it again in 2017! I would like to thank the CMTAA committee for their guidance and support in assisting the SA CMT Team in their CMT awareness work. The new CMTAA committee formed at the August AGM is an amazing group of passionate volunteers that I had the privilege of meeting at the October CMTAA strategic management forum this year. I look forward to working with the new committee in 2017. I would also like to acknowledge the tonne of work that the CMT Aussie Kids' leaders Jillian and Peter Critchley do, and remain optimistic that an SA CMT kid/s will be provided an opportunity to attend the amazing camp proposed for 2017. Finally, I specifically would like to thank the SA CMT Team: Lisa for her ongoing support with my role and for her work in the northern area. I also wish to thank Simone, Andrea and Isabella for their support of the team, their work in their local areas and assistance with various initiatives. The final (Christmas celebration) event for 2016 is proposed to be a two-hour Port River cruise with the dolphins followed by a coffee/lunch at the Port. More details will be emailed and posted on social media. Hope to see as many of you at our last event, but if not, a very Merry Christmas and a Happy New Year to all! We hope to see and hear from you in 2017 -

Take care and KEEP MOVING! **Antonia, Lisa, Simone, Isabella and Andrea - Your SA CMT Team**



WESTERN AUSTRALIA

Just a short note from WA to confirm our meetings are continuing, with the next one being scheduled for Saturday 5 November 2016 (2.00-5.00pm) at The Genetic & Rare Disease Network at 37 Hampden Road, Nedlands.

We're having two presentations, one from Monica Elberink following up on her presentation last year in relation to 'Remedial Massage and its Benefits and the second from Chris Murphy regarding his experiences with 'IVT testing as part of family planning'.

We continue to aim for having at least three meetings per year and the committee is already looking at presenters for 2017. However, we're very happy for our members to put forward suggestions but our meetings are also a very important social event.

We find that so much information can be exchanged over a cup of tea and a piece of cake!!

With best wishes for a Merry Christmas and very Happy New Year from all of us in WA. **WA CMT Committee**

Our CMTAA—The Way Forward

Your new Committee created a new 'first' for our Association in mid-October when we gathered, with other key friends to participate in a Strategic Planning Day. To kick things off many of us traveled to Sydney the day before, enabling us to have a meal together and get to know each other. Most of our gatherings are by teleconference these days so a face-to-face opportunity was a great way to start a new Committee.



Our Association has been on a steep upward trajectory over the last few years in terms of upgrading our administrative systems; web site; social media; office support; financial management; and member communications. In addition we have managed our biggest project ever, the compilation of two significant publications completed by the University of Sydney through government grants allocated to CMTAA Inc. We have also conducted the first international CMT Kids Camp. These successes have also raised our profile, and now we need to step back and take a more strategic look at where we wish to be in 3 to 5 years. Hence the Strategic Planning Day.

Most progressive organisations manage a 3 year rolling cycle of Strategic Plans. These start with a helicopter view of the organisation's area of influence commencing with the Vision, then progressing through their Mission Statement, Goals and Outputs for the planning period. Strategies are then drawn from this work and when implemented are considered important to achieve these goals.

Our previous President Darryl prepared a comprehensive SWOT analysis covering our Strengths, Weaknesses, Opportunities and Threats. With this background the excitement in the room grew as the ideas flowed. Our immediate objective was 'brain-storming' rather than decision making. The day was seen as a step in a process which will continue through our Committee meetings and flow through to you our members for your feedback and ideas.

A highlight was a dedicated session where we heard from some of our Sydney based researchers. Professor Josh Burns made us his first stop on his return from meetings in Bangkok, and Professor Garth Nicholson was there to give us a vision for where international research is leading. I heard the term 'cure' used for the first time. Dr. Scott Denton then reviewed his recent work on the report for the Department of Health and the booklet 'Moving Forward with CMT'.



Our afternoon was structured around a range of elements including liaison with other groups; governance; financing; marketing; communication; supporting our youth and you our members. We recorded the whole day and the transcription will provide us with ideas to consider and implement over the next few years. Watch out for further articles in this newsletter, our web site, and through Facebook.

Robert Twin
Treasurer

CMT AWARENESS MONTH FUNDRAISER SUCCESS

It was decided as a family project, that a fundraiser for CMT Awareness month was a great idea. We came together and liked the idea of holding a high tea. The high tea would be a tasty and worthy fundraising event to raise money as well as promoting awareness for CMT. With the support from the CMTAA we started to collect donations for the day. Donations were given in the way of venue, tea, prizes for raffles, vouchers to purchase food and of course valuable support on the day in the way of cakes and slices for the event. The event exceeded our expectations as we originally were hoping to cater for 40 people, 65 people came along on the day to support our high tea fundraiser. Amazing outcome, a great afternoon was had by all. Outcome for the event

was \$3,332 that has been donated to the CMTAA towards research. A huge Thank you to all involved.

Karen Roberts,
CMTAA member and
Mum to a CMT Aussie Kid



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CMTAA on The International Stage

VENICE, ITALY SEPTEMBER 2016



Beautiful Venice



Our Theme



The Home of Gondolas

Your CMTAA was represented at the recent 6th International Charcot-Marie-Tooth and Related Neuropathy Consortium (CMTR) Meeting by former CMTAA President, Darryl Beitsch, who was holidaying in Venice with his wife Robin. The theme of the consortium was “Together We Can”.

The consortium provided the opportunity for leading international researchers, including Professor Joshua Burns from Australia, to meet together and to present their research outcomes. This was followed by the international patient advocacy groups to share what was happening in their respective countries.



International Patient Advocate Representatives

Presentations were received from CMT France, CMT UK, Neuromuscular Disease Association Belgium, Hereditary Neuropathy Foundation USA, Dutch Neuromuscular Disease Foundation, Mitofusion 2 Project Group Italy and our CMTAA.

The CMTAA presentation covered:

The very successful survey carried out by Dr. Scott Denton to obtain data for the recent report that we submitted to the Australian Federal Government titled “Reducing the Health Burden of Charcot Marie Tooth in Australia 2015”.

The booklet we produced as a result of the report.

The recent CMT Aussie Kids camp that had children from CMT UK attending.

All presentations were translated into Italian and all were well received. It also gave the CMTAA the opportunity to showcase our achievements. Quite a challenge having to talk slowly, stop regularly, and allow the translator to completely communicate to the Italian audience.

All the representatives acknowledged that this was a wonderful opportunity to meet one another and properly apply the theme “Together We Can”. We are now building upon the positive rapport that was established with the view to increasing international patient group collaboration as we improve the management of CMT and assist our medical researchers.

CMTAA FUNDING RESEARCH

At our recent AGM, CMTAA presented grants to two of our esteemed researchers. **Associate Professor Marina Kennerson, Principal Research Fellow at the ANZAC Research Institute** at Concord spoke of her research and received a cheque for \$14,000



Project Overview: The overall project is to study structural variation as a mutation mechanism in CMT and other hereditary neuropathies to identify genes in motor neurons that will be disrupted due to large (millions of base pairs) DNA re-arrangements. This project will provide important cell biology technologies that will keep the CMT gene discovery program ANZAC Research Institute at the forefront of international translational research for this disease. The technology will allow patient skin cells to be made into motor neurons via iPSC cell re-programming technology which will be the ideal cell model to investigate disease causing processes in motor neurons. The paradigm-shift to use patient iPSC lines to model tissue specific (motor neuron) neurodegeneration is an important approach that must be adopted by the CMT research community to increase the chances of developing active treatment therapies.



Professor Joshua Burns, Professor of Allied Health (Paediatrics), Sydney Children's Hospitals Network received a grant of \$9722 to go towards his research into 'Personalised orthotic therapy for people with CMT using 3D printing technologies'.

Project Overview: Ankle-foot orthoses (AFOs) are commonly prescribed for children and adults with Charcot-Marie-Tooth disease. 3D printing, also known as additive manufacturing, has the potential to transform the way AFOs are prescribed, designed and manufactured. 3D printing offers geometric freedom to produce strong and lightweight devices that can be rapidly customised to meet individual patient needs.

The goal for this innovative area of research is to produce 3D designs of AFOs for children with the most common neuromuscular disorder, CMT, to rapidly prototype them using 3D printing, to trial these prototypes in relevant human trials, and translate their use into clinical practice.

The CMTAA are proud to continue to support research into CMT with the help of members donations. To donate to CMTAA go to <https://www.cmt.org.au/control/donate>

CMT AWARENESS MONTH

Our CMTAA Facebook page conducted a CMT Selfie Challenge asking people to post something they've been proud of. Here are a few of the inspiring words...

* I am 1 in 2500 and CMT strong! I hate trying to take selfies! I am so fortunate to live on a beef cattle farm. It is a lifestyle that I love. My four wheel motor bike is my work horse. I use it to muster the cattle, check the cattle/water and in this photo I am fencing with my husband Alan. I use the four wheeler to ride along the

fence line to firstly run the wire out and then go along and clip on the wires on to the posts which is great exercise for my hands. Love it!!!



* I have CMT. I am a special education teacher. I am married to a very supportive husband, and have two wonderful teenage children. Last year we fulfilled a lifelong dream to travel overseas and visit family. We also had a few days at Disneyland. We wanted to watch the light show, but could not find a spot to sit or even stand! My then 11 year old daughter approached a staff member and said 'my mum has trouble standing up for long, is there anywhere she can sit?' The helpful staff member found seats for the four of us! I am proud of both my children for the independence they have developed from a young age, and the help they provide me when my husband works away.

* 6 weeks ago I fractured my knee. I'm wheelchair bound for at least 12 weeks. It has made life as a Mum of 2 little ones hard but they are what keep me going on the hard days. I'm also very blessed to have a wonderful husband who looks after us all. This will not beat me!!!

* 4 of my brothers and I have CMT. In 2014 all of us and a couple of sister-in-laws and nieces went 4 wheel driving in high country VIC. I was on a walker & the boys had walking sticks. It was a bit of a struggle at times, but our nieces helped out when needed and we all had a ball! It was great to spend time together in a relaxed situation.

* My husband took me on a tour when we went overseas and we went to a floating fish farm. I held onto his hand for dear life because the flooring was unstable and floating. I was so proud of myself for going and giving it a go. I did have to sit out much of the tour because it was dangerous for me but I am proud that I gave it a go.

* Travelling around Australia in a motor home and experiencing many opportunities. Pushing the limits walking through sand and bush walks. No time to sit around and say it can't be done - stretch a bit more each day where you can.

23 AUGUST—3 9



'Probably the CMT Aussie Kids Weekend was the best thing as it was good to discuss our similarities and differences with someone from the other side of the world. It was also really good to meet and have fun with them.'



'The trip was perfect.'

'I honestly can't think of any improvements.'

'It was perfectly executed and planned, everyone worked well together.'



CAMP SYDNEY, AUSTRALIA

SEPTEMBER 2016

‘Every day was such a joy and an amazing new adventure. I think I had the most fun at Cronulla Beach, but the Berry Kids Weekend was my highlight, especially the last day and the BBQ that followed’



‘Going to Manly Beach was great as it was really interesting hearing from Mike Carroll and his story’.



‘Obviously the Berry Kids Weekend was so useful to build up relationships and for the kids to make international friends. I think everyone instilled confidence in each other and there was so much to learn from one another. I also think the BBQ with the families and supporters was very useful. I think it was lovely to interact with people who have the same goals and desires and for them to see how their fundraising helps first hand. I think there was a lot to learn from their opinions and a lot to learn from the way Jillian and Peter run weekends and to also see how people cope with CMT differently. The whole trip was important and helped the kids bonds to develop deeper so they really came out of their shells.’



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NEW ZEALAND *Vacant*

NEWS AND VIEWS

SUPPORT CMTAA

Last year your Association was approached with another through a third party to establish a regular donation through workplace giving. This set the Committee on a potentially new path for raising funds to meet our objectives, and I'm pleased to report that this option is now in place. Workplace giving is when an employee seeking to support a worthy cause can nominate an organisation which is recognised by the Australian Tax Office to accept tax deductible gifts, and then donate through their employer from their gross salary thus giving an immediate tax advantage. In some cases the employer will match the donations and/or cover the administration costs for the third party company through which the donations are managed.

There are 2 main third party companies operating in this space in Australia and we have registered with both to maximise our chances of driving donations. The advantages to companies of workplace giving include connecting donors to charities, and enabling companies to support the charitable inclinations of their employees and to be seen as good corporate citizens both internally and externally. For charities, the advantages include simplified management of many of their donations, improving end-of-year reconciliations and reducing administration costs and complexity.

The first company we have linked to is 'Good Company' (www.goodcompany.com.au) which supports over 1,500 charities and offers support for finding volunteers in addition to donors. Our link is at <https://www.goodcompany.com.au/charity/Charcot-Marie-Tooth-Association-of-Australia-Inc> and a donor can either use their existing login or register as a new donor.

The second company is 'Good2Give' (www.good2give.org.au) which supports over 1,300 charities. This site is managed by Charities Aid Foundation Australia a not-for-profit which has a focus on streamlining donations to the sector. A potential or existing donor logs in at <https://my.good2give.org.au/> and can then select CMTAA Inc as their preferred charity.

Your Committee will monitor these links and continue to enhance them to attract donors who may or may not be impacted by CMT. You can help us by promoting this option to your friends, many of whom may already be registered through their employer. Let's see if we can turbocharge our donations to enable us to do more to help all those with CMT. For further information please contact me on 0409 840042 or at Treasurer@cmt.org.au.

by Robert Twin Treasurer CMTAA Inc.



MOVING FORWARD WITH CMT

The Charcot Marie Tooth Association of Australia (CMTAA) is very excited to bring you a new publication 'Moving Forward with CMT'.

It is an insightful, informative and entertaining look at CMT in Australia and was produced by Dr Scott Denton and his team; the same team behind the recent survey on 'Reducing the health burden of Charcot-Marie-Tooth Disease in Australia'.

The book can be downloaded online at <https://www.cmt.org.au/control/news/moving-forward-with-cmt>

Or should you require a hard copy, please contact our National Office. The cost is \$5 which covers p/h.

Can you help?

Professor Joshua Burns and Melissa Mandarakas (Physiotherapist and PhD Candidate) at The Children's Hospital at Westmead are conducting a project with the Inherited Neuropathies Consortium, involving the development of the CMT Infant Scale.

Most forms of CMT begin in childhood and progress throughout a person's life time. Current research suggests that treatment to slow disease progression may be most active if introduced early in a patient's life before muscle weakness and sensation loss develop, as it may be easier to slow disease progression than to reverse disability that is already in place. Clinical outcome assessments have been developed for adults (CMT Neuropathy Score) and for children 3 years of age and older (CMT Pediatric Scale). However, no CMT-specific clinical outcome assessment currently exists to measure disease severity or progression in children from birth to 3 years of age. It is the goal of this study to develop and validate the CMT Infant Scale.

Families with children aged 3 years and under who would like more information can contact Melissa Mandarakas, Study Coordinator at Melissa.Mandarakas@sydney.edu.au

Did you know?

Wheelchair rugby is a fast paced team sport which is played by males and females that have a disability that affects at least three limbs. Wheelchair rugby is played on a basketball court and the object of the game is to score goals by crossing your opponent's goal line while in possession of the ball.

Victorians living with CMT disorder may be interested in trying the sport. Disability Sport and Recreation has programs running for beginner's right through to the elite level with coaching and equipment available.

Wheelchair rugby is the most physical of wheelchair sports and specially reinforced wheelchairs are used to handle the hits laid by the opposition while they attempt to prevent you from scoring. Wheelchair rugby is played in over 30 countries worldwide and is one of the highlights of the Paralympic Games.

For more information about Wheelchair rugby please contact

Jason Lees, DSR Wheelchair Rugby Coordinator on (03) 9473 0133 or jason@dsr.org.au



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Step 2: Email us at cmtaa2@cmt.org.au letting us know of your donation.

Step 3: Smile! Feel good about yourself! Your donation will ¹⁶go to help people with CMT.

CMT AUSSIE KIDS WEEKEND

26-28 AUGUST 2016 BERRY, NSW, AUSTRALIA



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FOR MORE DETAILS: cmtaussiekids@gmail.com

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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 Podorthist—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 2017

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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

Email: cmtaa2@cmt.org.au

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

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