

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 87 Summer 2017



CMTAA
Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

CMTAA GRANT RECIPIENTS FOR 2017

CMTAA is proud to support Medical and Allied Health Professionals in their research into CMT.

Professor Joshua Burns from the Sydney Children's Hospital Network, The University of Sydney and Dr Alison Shield, Faculty of Health, University of Canberra were the successful recipients of this year's grants offered by the CMTAA. Thanks to the generosity of members the CMTAA has been supporting research into CMT for many years.

The subject of Prof Burns' submission 'Exercise is Medicine for Charcot-Marie-Tooth: Translating research into Practice' explains the first effective muscle building therapy for children with CMT and describes the next step in developing a translation strategy to directly impact clinical practice and improve health outcomes for children and adolescents with CMT, locally, nationally and internationally.

Dr Shield's submission 'Medication Safety and Charcot-Marie-Tooth disease: Engaging the Pharmacist' will continue the work she has been undertaking to bridge the gap in medication safety. Both will add to the body of knowledge and continue to support CMT sufferers.



Both Prof Burns and Dr Shield were in attendance at the recent CMTAA National Seminar where they were presented with their grants by CMTAA Treasurer

Robert Twin.

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

PRESIDENTS REPORT



Hi all – I'm pleased to introduce myself. I am a fellow CMT sufferer with X linked CMT (thanks mum). I am the only male in my family with this CMT so fortunately my daughter and cousins, while feeling CMT's curse are less impacted. I consider myself lucky as it hasn't significantly impacted me getting on with my life – obviously, I never won a running race at school, take 5 times as long as anyone else to get dressed and my hand writing can only be deciphered by highly skilled technicians. A couple of tendon transfers in my hands (thanks Professor Tonkin) and an ankle fusion (thanks Dr Ellis) and I'm as good as new - although I have now come to realise that my dream of playing for the Wallabies is probably fading.

I was diagnosed in my late teens following years of ankle problems – fortunately my mother was very tenacious and we didn't stop visiting doctors till we found out what was going on. I was diagnosed by a paediatrician who invited my mother to squat to the floor to observe my early stage footdrop – it can now be seen by the naked eye from the moon!

I believe that the CMT association is very well served by your committed and hard working committee members and state and regional coordinators. I look forward to working with all of them.

My personal goal as President will be to work on increasing the awareness of CMT within the medical and allied health communities. I would like to see CMT diagnoses being made faster through better GP knowledge and also help to develop knowledge of those practitioners who are helping people with CMT. This will be a major task and we will not see results quickly but I would like it to be my focus so the rest of the committee can continue with their existing wonderful work and priorities.

If you are able to provide me with assistance on my project please let me know – perhaps you are a marketing expert or marketing student, or perhaps you are employed within these industries and can offer me advice and direction – if so please contact me on President@cmt.org.au

Thank you for the confidence you have placed in me on my election to be your President. I will endeavour to serve you all well but don't hesitate to contact me if you think I could do with some "suggestions".

Be kind to yourselves

Tony
CMTAA President

NEWS FROM THE REGIONS AND STATES

GOLD COAST

Hi all, Judy here from the Gold Coast, things have been very quiet lately, due to me having foot surgery, although it is a long slow recovery I feel like I am making progress. I would like to congratulate our new President , and board members, I am here to help in any way I can, and from what I have heard the Seminar was an outstanding success, so a big well done to everyone involved. I am so proud of how the fundraising is going to enable the kids to get to the U.K, wishing you every success.

The Gold Coast Gangs next get together will be on Monday the 20th of November at the Club Southport (C.S.I), Scarborough St Southport, starting at 10.30 am, this will incorporate our Christmas Lunch.

I would like to wish you all a very Merry Christmas, and a safe, happy and healthy New Year. So until next time, take care and keep smiling, God Bless, Judy.

AUSTRALIAN CAPITAL TERRITORY

The ACT Support Group met on 11 October at another new venue. This one is in central Canberra, so reasonably convenient for both north- and south-siders. It is a plush boardroom, with all mod cons, and should be an excellent home for future meetings. As Murphy's law would have it, the inbuilt AV system, which was tested just 5 days earlier, refused to work! However, we were rescued from disaster with a hastily rigged bypass and all was well.

It was great to welcome two newcomers to the group. They both had lots of questions – this is exactly what the support group is there for. We also watched Prof Garth Nicholson's address to the recent Awareness Day on the status of current CMT research and where it appears to be heading in the future.

I recently met with a representative of the Capital Region Muscular Dystrophy group, who asked me to support them in lobbying the ACT Government for the establishment of a neuromuscular clinic at the Canberra Hospital. I wrote to the Health Minister and received a reply indicating that discussions are still ongoing, but she also mentioned that Neuromoves, a specialised gym for people with spinal cord injury or other neuropathic conditions, will open in November at the Flynn Community Hub. This may be of interest to our members.

This was our last meeting for the year, so I'd like to wish everyone a very happy Christmas and a healthy 2018.

Gabrielle Evans
ACT Coordinator

TASMANIA

The Tasmanian Support Group continues to grow with 2 new folk contacting me in the last 2 weeks – this is great – the word is getting around!

We will be having our Christmas Coffee and Chat on Sunday 12th November at our home – may have to look at a new venue for these get-togethers as numbers grow!

I had an amazing time at the Sydney Awareness Day with great speakers, Nastasia Campanella being especially inspirational – not only does she have CMT but is also blind. It was good to hear Alison Shield and Scott Denton with the results of their research from the focus groups that we participated in. We also heard from the CMT Aussie Kids which attracted 30 youth attendees plus adult leaders to their camp this year. Would love to get some "Tassie Kids" to one of these camps! CMTAA was able to give Josh Burns and Alison Research Grants - Josh to develop an exercise program for adults and Alison to develop information to be given to Pharmacists regarding medication and CMT. Thanks also go to Darryl Beitsch for his information package "I Have Been Diagnosed with Charcot-Marie-Tooth Disease – What Happens Next?" I hope to take copies of this to the Neurologists in Hobart to hand out to newly diagnosed folk. There is so much to tell our Support Group when we meet!

Special thanks go to all the folk at Concord for the incredible job they did in hosting the Sydney Awareness Day – congratulations! Marilyn Kremmer, Tasmanian Coordinator



NEWS FROM THE REGIONS AND STATES

WESTERN AUSTRALIA

Following our August meeting and the small number of people attending, the WA Committee has been working hard to secure new and interesting presenters for future meetings. We have reached out to a number of local associations and individuals seeking their advice and input for future meetings.

As a result, we have secured Vivienne Travlos, a lecturer in paediatric physiotherapy at the University of Notre Dame Australia, clinical physiotherapist at Princess Margaret Hospital for Children to address our next meeting.

Further information will be circulated and/or posted out to WA members next week.

Details of the next meeting are: Saturday 18 November 2017 (2.00-5.00pm), Oasis Lotteries House, 37 Hampden Road, Nedlands. Please note the date, as some members may have received advice of a different date in November.

This is our last meeting for 2017 and we hope to see our WA members on the day.

Best wishes for Christmas and have a safe and happy New Year. CMT WA Committee

SOUTH AUSTRALIA



A warm Hello from the SA CMT community. What a busy quarter for SA. Hope everyone had a Happy International CMT Awareness September! I am happy to report SA certainly did as we continued to spread CMT awareness through a number of activities. Your CMTAA SA Support Group continues to keep CMT information material across various Councils, Community centres, GP rooms, Hospitals, Allied Health Professionals, schools and childcare centres. If anyone wishes to distribute materials in their area or would like some for family and friends please contact us. The SA Group has also been busy out there in the community raising CMT much needed research funds when they participated for the second year in the City to Bay Fun Run, 17 September. More than \$400 was raised! Activity on the closed SA CMT Facebook was kept particularly active throughout September. With more than 50 members and growing thank you to everyone for their posts, keep them coming. If you wish to keep connected to the local and national CMT scene we invite you to join. So why not contact us?

September was an important month also for the CMTAA National seminar in NSW, 24 September. A big thank you to the CMTAA committee, especially Anycie and Jillian and Robert. An excellent seminar that I was fortunate to attend and found enjoyable and extremely informative. Friendships were made and sharing was encouraged. Congratulations, to the new CMTAA team (and SA once again is represented by yours truly). A big welcome to Tony Adams our new President. Thank you Tony for taking the time to make contact with the CMTAA SA Team in your first month of office, greatly appreciated. On 27 September we also were represented at the MDSA (Muscular Dystrophy of South Australia) at one of their CMT support sessions. On 21 October we enjoyed our Coffee and Chat session in the West at Ikea. Another big event for SA was the CMTAA stand at the Disability, Ageing and Lifestyle Expo: My Life, My Choice at the Adelaide Show grounds, 27 October. This is the second year CMTAA SA CMT Support has participated. An excellent way, to increase awareness and connect with the many providers of services in and out of the NDIS space. Please call me to share the latest information, which will also be shared as a folder on the SA Facebook. Busy busy time for SA!! Still a number of activities to go though. A CMT table is being arranged at the MDSA Xmas lunch, 2 December and a Xmas break up at the MDSA support group 17 November. Call me to see how you can join us. If anybody is interested in joining the SA (volunteer) Support group I would love to hear from you. Finally, a big thank you to the CMTAA SA Support team, Lisa, Simone, Andrea, Isabella for all their support throughout the year. A special thank you to Lisa for all her social media work. On behalf of the team we would like to wish you a Very Merry Xmas and a Happy and Safe New Year xo



HELP WANTED



- *Are you a marketing expert or student? Could you assist with the development of our marketing plan to increase awareness of CMT within the medical community?
- *Are you currently employed in the broader medical community and could offer advice on our strategies for awareness increasing?
- *Do you have a good working knowledge of Microsoft Access? Could you help write some simple management reports off our existing Access database of Members
- *Are you an IT guru based near Sydney who can help us maintain our network and file management for our Windows 10 office computers. It's not a big job but we could do with some more knowledgeable people helping with this

If you are able to assist with any of these please email Tony on President@cmt.org.au

VICTORIA

Life has its ups and downs and recent months have been a challenge for me, I had a fall and dislocated my kneecap, ouch! This is the sixth time I have been on crutches so I am no stranger to having to cope but this is the first time on crutches as a result of an injury, previously it had been planned surgery! I am happy to say I am on the mend but it now means I need to revisit my footwear and possibly looking at a brace for my left leg, wish me luck on that journey. Before my injury we had a visit to The Independent Living Centre which was very informative, the ILC has displays of products that supports people to perform a task that they would otherwise be unable to do, or would have difficulty doing. The occupational therapists at the centre are very helpful so those that weren't able to attend please feel free to visit when it suits you, they have a centre in Braybrook and Blackburn and can be contacted on 1300 885 886.



Unfortunately, I missed the seminar in Sydney but I hear it was a huge success so I hope that those of you who were there found it useful. The weather is slowly warming up in Melbourne, warm one day and cold the next, so once I get the next round of specialists out of the way I will send out details for our next catch up. Please note I understand that not everyone can travel to the events held in the Melbourne metropolitan area so it would be ideal if Victoria also had regional coordinators. I would be happy to assist in organising regional events if you would like to nominate to be a regional coordinator. Please feel free to contact either myself 0419 351 765 or the CMTAA Team 02 9767 5105.

I hope you are all well and have survived the winter months and are looking forward to summer.

Warm Regards, Paula Hodgson, Victorian Support Group Coordinator

NAMBUCCA HEADS

We have been sorry to hear that our Nambucca Heads Area Coordinator Meryl Grew has been laid up in hospital for a while, with the expectation of another month or so 'inside'. Meryl, all of your friends at CMTAA wish you a speedy recovery.

CMTAA NATIONAL SEMINAR –24TH SEPTEMBER 2017

'Absolutely inspirational', 'fabulous', 'relevant', 'valuable', 'knowledge', 'informative', 'support', 'relaxed, welcoming atmosphere', 'networking', 'resources', 'new friends', 'well organised', 'learning', 'amazing' and 'positive'.

These are all words taken from the feedback forms from this year's CMTAA National Seminar at Concord Medical Education Centre at Concord Hospital. We were proud to welcome close to 100 members of our CMT community, supporting one another and learning about the latest developments, sharing stories, learning new ways to manage their CMT, and what CMTAA has been doing to champion CMT in Australia.

The packed program included speakers from all areas and interests. This year including Prof Garth Nicholson speaking on CMT Research, Prof Joshua Burns on Management of CMT, ABC Radio personality Nas Campanella, Pedorthist Karl-Heinz Schott, Occupational Therapist Mandy Hanna, Assoc Prof Alison Shield speaking on Medications and CMT, and Dr Scott Denton, author of the groundbreaking survey 'Reducing the Health Burden of CMT in Australia'. As always the CMT Aussie Kids presented news about last years and this years camps along with exciting developments in their planned UK CMT Camp in 2018.

In an exciting development this year for the first time we ran a half day seminar just for kids called 'Kids Matter'. Run by kids, for kids, with stuff kids want to know...and pizza for lunch. Mandy Hanna, Occupational Therapist from St George Hospital in southern Sydney, Jo Vercoe, Disability Liaison Officer at the University of Wollongong and Melinda Myers, Psychologist spoke to around 10 kids informally in a way that was both engaging and informative.

The importance of getting together as a community cannot be underestimated. To feel you are not the only person struggling with the challenges CMT brings every day. The seminar provided opportunities for attendees to chat, share stories and learn from others. Stay tuned for details of next years CMTAA 2018 National Seminar.

CMT AUSSIE KIDS Eleanor, Josh and Matilda meet inspirational speaker Nas Campanella

Prof Joshua Burns (centre) catches up with Nas and her Mum Tonia.



CMTAA AGM

The CMTAA AGM was held after the National Seminar and we congratulate the newly elected committee. From left Robert Twin (ACT) Treasurer; Antonia Karydis (SA) Committee Member; Jillian Critchley (NSW) Committee Member; Marilyn Kremmer (Tas) Committee Member; Tony Adams (NSW) President; Anycie Bergmann (NSW) Secretary. We look forward to the year ahead with optimism and excitement.



CMT AUSSIE KIDS NEWS



2017 Camp

We have attended our camps at Berry on the south coast of NSW for 5 years, and loved every minute of it.

Throughout these years over 40 kids have experienced the comradery and excitement of meeting someone else who understands what it's like to have CMT. And this year we were excited to try something new. Nearly 30 kids aged from 9 years hopped on board the Sydney ferry to Cockatoo Island, Sydney Harbour on a Friday evening in August to experience camping under the stars, and

friendships made for life. The group, enjoyed a surfing morning run by Surf Educate Australia (SEA) at Manly Beach, joined by Professor Joshua Burns (or just Josh to the kids); campfires; a Checkpoint Challenge around Sydney CBD; movies screened in a building built in the 19th century and exploring Cockatoo Island and it's shipwright history. As one of our supporters said '...the camp brought our children together as a group to socialise and bond in a caring, non-competitive and empathetic atmosphere. ...' Well done to all!

As in previous years we sent out a survey to both attendees and their parents to get feedback on the camp. Following on from the survey results **we have decided to not run a Kids Camp next year.**

This is due to a number of factors including:

Feedback from the survey shows us there is a strong preference to a camp in the early part of the year (Feb/ March/ April) and we feel there would not be enough time, or interest in a camp in this period in 2018. It would only be 5 months between camps.



Peter and I will be heavily involved in arranging the reciprocal UK visit in July 2018. Our time, like all volunteers is finite and we need to prioritise to ensure the kids get the best out of us.

However, having made that decision we have a couple of new plans we are working on.

New Venues to explore– We have been encouraged by the Cockatoo Island experience and will explore the 'Glamping' aspect of the Cockatoo Island set up. We have also discovered another school type dormitory accommodation at Chowder Bay, that may meet our needs, which we will investigate further.

Sailors with DisABILITIES– During the Seminar Peter was approached by a gentleman David Leslie, former Chairman, board member and volunteer with Sailors with disABILITIES (SWD). He discussed the possibility of supporting one of our kids camps, and/or involving older adults in the SWD program. The activity involves a day on Sydney Harbour on one of their 50 ft yachts, with the participants involved in as many aspects of the sailing as possible. They sail out of Rushcutters Bay and the activity runs for approx. 3-4 hours. The SWD normally take out school groups, so they are already well set up with Working With Children checks and other necessary paperwork to ensure the safety, well-being and enjoyment of all participants. We will investigate this further with David and keep you all updated. However, let it be said, we're pretty excited about the potential for this activity to further extend our CMT Aussie Kids and CMTAA programs.

UK Fundraising Efforts

The enthusiastic group of kids selected to travel to the UK next July to attend the CMT UK Kids Camp continue to amaze us with their fundraising prowess. High Teas or 'CMTeas' as one fundraiser coined were 'high' on the list of events run. Peter and I travelled to Yass, Canberra and northern Sydney to support these amazing kids. Not only are they raising funds for the trip, but are raising awareness of CMT. Their positive approach to their condition is humbling, and we are proud to call them all CMT Aussie Kids.



The flights are booked and paid for—all by individual fundraising efforts—no mean feat when you consider the cost of international travel), the itinerary is firming up, and we are excited to join the UK kids on their 4 day camp in the Lake District. Sightseeing in London and Edinburgh, along with exploring the English countryside will keep us busy for the 2 weeks we are away from



Australia. We know these kids will be amazing ambassadors for CMT.

Jillian and Peter Critchley with Sarah (left) and Josh (right) 2 CMT Aussie Kids fundraising for the trip of a lifetime.



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NORTHERN TERRITORY

Darwin

Mrs. Kaye Bartlett (See above)

NEW ZEALAND Vacant

THANK YOU for donations from 16th July 2017— 31st October 2017

DONATE TO CMTAA

\$500 and over

In memory of Julie-Anne Holmes

\$200—\$499

Murrayville Community Mr. R. Hill Mrs Hilda Newstead SA Fun Run
Grill'd Restaurant, Miranda—application made by Peter and Jillian Critchley

\$100—\$199

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Mrs Margaret Adams	Miss Fionna Davies	Mr James Koios	Mrs Elizabeth Lumsden
Mr David Sherley	Mrs. Carol Newman	Mrs Valerie Fennell	Mr Julian Ferenc
Mr. Raymond Willis			

\$0—\$19

Mrs Helen Ward

DONATE TO CMTAA

Please follow the steps below to donate to the CMTAA:

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

OR

Electronic Funds Transfer payment : 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.

R—Donation to research

A—Donation to administration

Y—Donation to CMT Aussie Kids Youth Activities

Please email us at cmtaa2@cmt.org.au letting us know of your donation.



CMT Aussie Kids is a youth program run by the CMT Australia. It supports kids with CMT and gives them opportunities to 'play' as equals with peers with the same condition, learning to manage and **respond positively** to the difficulties and challenges they confront every day.



In July 2018, **nine CMT Aussie Kids** are heading over to the UK to attend a 4 day CMT Kids Camp in Keswick, Cumbria, getting to know their British CMT counterparts and touring the country for 2 weeks.

We have created a **GiveNow donation page** where family, friends and supporters can donate to help make our trip a reality.

Go to

<https://www.givenow.com.au/cmt>



NOW AVAILABLE

CMTAA SEMINAR 2015 DVD

Prof. Garth Nicholson – CMT Research and Achievements

Mr. Michael Carroll: My Life with CMT

Dr. Manoj Menezes – CMT in Childhood: Trials and Interventions

Dr. Scott Denton: Reducing the Health Burden – project update.

Workshop: Prof. Garth Nicholson, Prof. Joshua Burns and Mr. Darryl Beitsch

CMTAA SEMINAR 2016 DVD

Prof. Garth Nicholson – CMT Research and Achievements

Dr. Desmond Soares, Surgical procedures to benefit hand, foot and ankle problems.

Mr. Darren Pereira, Orthotist: The use of Orthotics in Managing CMT

Mr. Ernie Tye, Pedorthist: Custom Appliance Application Based Footwear

Question and Answer Session: Professor Garth Nicholson

These newly released DVDs are available from the National Office for \$25 each (including postage and handling). Order your copy now by phoning (02) 0767 5105 or email: cmtaa2@cmt.org.au

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

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: cmtaa2@cmt.org.au

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ARTICLES AND IDEAS

Your letters and articles are very welcome. This is your newsletter. Let me know what you want. Ideas, letters, articles, photos, anecdotes...anything is welcome that is CMT related.

Deadline for next newsletter: 31st March 2018

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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

Email: cmtaa2@cmt.org.au

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International Awareness for Charcot-Marie-Tooth disease

Find out more at
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