

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 80 Winter 2015



CMTAA
Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

FIRST IVF BABY BORN AFTER NEW TECHNIQUE TO ELIMINATE GENETIC DISEASE

The first baby in Europe has been born following a new IVF-based technique developed to prevent the inheritance of genetic disease.

The screening technique, called karyomapping, is a type of PGD (preimplantation genetic diagnosis) procedure. Current PGD methods are developed on a case-by-case basis to test embryos for the presence of a specific mutation found in one or both of the parents' DNA and can involve months of laboratory work.

Karyomapping, on the other hand, can test for the same diseases, but can be completed much faster and is no more expensive than traditional PGD methods. It can also be used to check that embryos have the correct number of chromosomes.

Mrs Carmen Meagu suffers from Charcot-Marie-Tooth disease. She inherited the disease from her father, and had a 50 percent chance of passing it on to her children. The technique involves using DNA from Mrs Meagu, her husband Gabriel, and another family member, to compare roughly 300,000 different points across the genome called SNPs (single nucleotide polymorphisms). This allows scientists to find characteristic features that are unique to the chromosome carrying the defective gene. Following a standard IVF cycle, embryos are biopsied to find out which ones are free of the genetic disease.

Mr Paul Serhal is the founder and medical director of the Centre for Reproductive and Genetic Health, (*Ed: in the UK*) where the technique was used in December 2013. Mr Serhal explained: 'Essentially, karyomapping finds a fingerprint that is unique to the chromosome that carries the defective gene.

'It is then possible to test embryos produced using IVF for this presence of this fingerprint. Whenever the fingerprint is seen in an embryo it means that it has inherited the chromosome carrying the defective gene. The test checked for Charcot Marie Tooth disease and at the same time for chromosomal abnormalities, such as Down's syndrome, enabling us to avoid inadvertently transferring an embryo which may otherwise not have been viable.' (Published by CMTUK, used with their kind permission)

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

PRESIDENTS REPORT with Darryl Beitsch



Dear CMT Friends,

We are now well into another winter season – not the favourite time of the year for our “CMT Family” with cold legs and feet. Nothing like an electric blanket as an important winter management tool!

When I was re-elected as your President for this current term, my 8th consecutive term, I advised the AGM that this would be my final term as your President. From a personal perspective, it has indeed been a pleasure to serve you over these 8 years. Together with your hard working management committee (we are all volunteers) your CMTAA is in a position that is beyond our wildest dreams. We have been punching well above our weight.

Membership has grown, our website has been significantly upgraded, we have revised our constitution (see separate article), changed our branding with a new registered logo, our Facebook page has over 500 “likes”, Regional Support Groups are active, growing and convening their own CMT Awareness Seminars, our Sydney Awareness Day Seminar has grown to include the Saturday afternoon prior to the Sunday Awareness Day and we now have a well established National CMT Aussie Kids weekend. We are also well respected on the international stage and through your generosity provide grants for our Australian CMT researchers. Additionally, I have had the opportunity to address Sydney University Exercise Physiology students to ensure they are aware of the reality of Charcot-Marie-Tooth Disease.

Your CMTAA was given the responsibility from the Australian Government to conduct the very first national research project regarding the health burden of CMT to the government and the community. This is being conducted through the University of Sydney. A big thank you to all who completed the survey and attended the Focus Groups. Your first hand input has greatly assisted Dr. Scott Denton and Prof. Joshua Burns in preparing the final report.

This leads me to 2 very important issues:

As a result of the fact that our 2 office volunteers are stretched to the limit and we have been unsuccessful in attracting additional volunteers, your committee has endorsed the need for casual paid assistance in our National Office. Please refer to the position description in this newsletter.

I am of the firm belief that it is in the best interests of our CMTAA that we have fresh leadership and ideas to build upon what we have in place to take us into the future. This provides an excellent opportunity to serve our “CMT Family”. Technology overcomes the tyranny of distance and your current committee are located locally and interstate.

I see it as my duty to alert you to the fact that if we do not fill the positions on our committee at our September 12 AGM, it is unlikely that our CMTAA can continue. Documentation for the SGM and AGM will be available for you in August.

This is my final message to you as your current President. Thank you for your confidence, trust and support over these past 8 years. I have had the privilege to meet and communicate with many of our “CMT Family” and have been inspired by the positive attitude and success stories that many of you have shared with me.

Take care and keep moving.

Darryl Beitsch

President



CMTAA Inc. National Office Casual Position Description

Personal Qualities

Essential that the applicant has a passion to assist people. The people we assist are those who have Charcot-Marie-Tooth (CMT) disease which is a genetic degenerative peripheral neuropathy. CMT is not life threatening but those with it have it for life. The primary objective of the CMTAA Inc. is to support our members and others with CMT by providing relevant information and encouragement to maximise their quality of life. For additional information about CMT and the CMTAA Inc. please visit our website www.cmt.org.au

Position Requirements

Be able to work on a Tuesday or Thursday during school terms, however this is negotiable.
Hours – flexible 3 to 4 hours per week within the time frame of 9.30am and 3.00pm.
Basic typing skills.
Practical knowledge of word and excel is essential.
Reporting to the CMTAA Management Committee

Duties

There will be a daily diary to be kept that would include recording the incoming calls and responses, preparing incoming postal mail (membership payments etc) for receipting.
Simple filing system.
Assisting three times a year with the emailing and postal mailing of our newsletter to members.
Answering incoming enquiries from mainly people requiring information about CMT and where assistance can be sought. This information is already available to give out. If in doubt refer the enquiry to either the CMTAA Secretary or President to action.
Entering of membership and donation payments in the bank deposit book.
Training will be provided after a settling in period of time regarding the membership and donation receipting process.
Responding to emails and phone calls after a settling in period of time.

Remuneration

To be discussed with the CMTAA Management Committee.

Please phone 9767 5105 or email cmtaa2@cmt.org.au to explore this opportunity in more detail.

NEWS FROM THE REGIONS AND STATES

TASMANIA

What a fantastic turnout we had for the Tasmanian Focus Groups as part of the Research Study being conducted by Scott Denton in June. We had to change venues at the last moment as snow was forecast down to 200 metres and as we live at 420 metres there was some last minute panic! The joys of living on a mountain! Fortunately I was able to contact everyone and we were able to have the use of a church hall. Thank you to all the Tassie folk who attended with some travelling from the north of the state to attend despite the cold and wet weather! It was lovely to meet Scott and Jill and the feedback from our support group members was enthusiastic. It was great for our members to sit around a table and discuss all their concerns with someone who understood what they are going through. It is so important that CMT folk can talk to someone and not feel isolated or alone. There is plenty of room for improvement in the Tasmanian health system if only we could convince the Government although I understand that there are similar concerns in other states.

Congratulations to CMTAA along with Scott and Jill for all their hard work in putting together such a comprehensive questionnaire that went out to members and other folk with CMT. I look forward to the final results of this.

I have had two more enquiries from new folk diagnosed with CMT and look forward to meeting them at our next meeting which I hope to have some time in August.

Once again, my thanks go to the CMTAA committee and office staff for all their hard work (especially as they are all volunteers)- it is certainly appreciated.

Kind regards, Marilyn Kremmer

GOLD COAST

Hi everyone! Judy here with greetings from the Cold Coast, or I should say the Gold Coast. I hope you are all well and keeping warm. Our meeting went really well even though a few of the regulars were away on holidays I had a few new faces come along which was great ! I have also been getting a few enquiries, thanks to the Web. I also had it mentioned on the community radio, and I also keep putting a notice in the local paper, so the word is spreading. I am really looking forward to find out the results of the survey. exciting times for the C.M.T family. Hopefully I will catch up with some of you in Sydney at the Seminar. Well, until next time, take care and keep smiling ! Judy.

AUSTRALIAN CAPITAL TERRITORY

The ACT Support Group met on the afternoon of Sunday 12 July, the coldest day of our year so far! Unsurprisingly, the turnout was not huge, but we kept warm and enjoyed lots of interesting discussion. We watched a presentation from a US CMT conference in which an orthopaedic surgeon talked about his biomechanical assessments of CMT patients and the decision-making processes leading up to surgery on hips, spines and feet. We generally hear a lot about feet and CMT, but not much about hips and spines. I was particularly interested, as I have suffered spinal pain and disability from childhood, decades before I was diagnosed with CMT.

At our next meeting, one of our members has volunteered to talk about her experience of successfully dealing with the NDIS application process. If you have thought about it, but been daunted by its complexity, do come along and learn about it. The date has yet to be arranged, but members will be notified by email.

Stay warm!

Gabrielle

NEWS FROM THE REGIONS AND STATES

SOUTH AUSTRALIA

We warmly welcome Dr. Andrea Pollock PhD, to the team as the eastern contact person for the SA CMT support group. Her enthusiastic input so far is greatly appreciated.

SA CMT Membership

Our CMT family is growing in SA. We currently have 15 active members. A sincere thank you to Lisa for all her hard work and efforts in updating our SA membership database.

SA CMT Facebook Group:

SA Facebook group numbers continue to steadily grow and currently stand at 27. However, activity also appeared to drop in June when we underwent a makeover of our Facebook page. We would like to apologise to our contacts for any confusion that may have been caused. The changes raised and instigated by the SA team meant that CMTAA Inc. have been able to adapt the CMTAA Inc. Logo and produce a more consistent and united front for all Australian state Facebook groups. We sincerely thank Kathy Mathews (Vice President and CMTAA Facebook coordinator) for her assistance. We invite you to visit our Facebook group for yourself at <https://www.facebook.com/groups/charcotmarietoothsa/?ref=bookmarks>.

Alliances

In May and June we have been attending regular gatherings and meetings at and with the Muscular Dystrophy Association of South Australia (MDASA). Our Alliance with MDASA enables us to have reciprocal advertising arrangements with MDASA in each other's website and newsletters. Attending MDASA meetings have been informative where the SA CMT team hope to further engage with the SA CMT community and share new information. MDASA have also agreed to provide us with assistance during the SA Awareness Day 19 September 2015 and in anticipation, we sincerely thank them.

CMT Survey

Antonia has been busy with the circulation of the CMT specific survey. This has led to us meeting with MDASA, the Repat Hospital, Disability Services SA and the Royal Adelaide Hospital. The Surveys however have been a little difficult to distribute through these channels given the red tape. What is very beneficial is the many network opportunities these are creating for the SA CMT Team. We intend to put these networks to work to disseminate CMT relevant information to their clients, and engender interest in the SA CMT Awareness Day and the through the SA team, the CMTAA Inc.

The SA CMT Questionnaire

The feedback so far has been extremely useful in helping us plan the awareness day event. Our contacts have provided good indications of topics they want covered, interest in attending and that the location is favorable.

SA CMT gatherings report

The May gathering in Murray Bridge was very fruitful. Despite 2 late apologies due to ill health, the 6 attending the afternoon made for a very pleasant and informative afternoon. Both Lisa and Antonia attended, and it was a great opportunity for us to meet more of our contacts (who are not members at this stage). Three hours flew by, the sharing was fantastic, topped off by our youngest member James holding the door open for everyone bidding all attendees a polite thank you for coming and goodbye.

We have planned another regional gathering on 25 July in the south at Victor Harbor at the Two Bees Café, 1a Ocean Road Victor Harbor from 12pm – 2pm. But please also keep an eye on the SA CMT Facebook group and MDASA website and newsletter.

Further gatherings in the, eastern and northern parts Adelaide are also planned to finish off the year. As always we invite you to contact us at any time to discuss what you would like to hear about in forthcoming SA CMT events.

Who, What, Where, When and How of CMT in SA Awareness Seminar

It is full steam ahead for this very important networking day and it could not be better timed as the NDIS rolls out. The event will be held on Saturday 19th September, from 9.30 am – 3 pm, at the Adelaide Pavilion, Veale Gardens. Full details will be posted on the national website and Facebook page and SA CMT Facebook group when finalized.

Warm regards Antonia, Lisa and Andrea

HAND CONTROLS by Kay Boreham

Are you considering getting hand controls for your car?

As I have been driving with hand controls for over 35 years, these are my personal views I thought I would share with you, and some considerations for you to think over before you embark on the journey.

The Car: There are a number of points to note when deciding to fit hand controls.

Power steering and power brakes (they are mostly standard on all cars now). Also comfortable seating that can be adjusted easily. I found that wide bodied cars did not give me easy access to window controls, so a medium make of car with window controls on the arm rest I found were ideal for me, as a woman.

Rear access is another consideration. As I have become weaker I have needed a walking frame when going shopping, therefore having a level boot access for the putting the frame, and shopping, into the car is much easier and safer. (I drive a Toyota Prius which has easy opening, level boot access, and also gives me the advantage of being more economical.)

Air bags can affect the placement of the hand controls. As knee air bags are being fitted to more and more cars, your engineering firm must be able to fit the hand controls without it affecting all the other airbags. Some companies can, others do not like to try.

A steering knob will be fitted to your steering wheel (the knob can be detached so others can drive the car) and a linkage (rods) and handle will be fitted to the brake and accelerator pedals. The handle control will be placed near the steering wheel at a position suitable and comfortable for you to use.

Important: Hand control fitting requires certification. The controls need to be fitted by a certified engineer and you are required to take the paperwork given to the RTA for them to approve.

Personally: How it Affects You:

The use of hand controls requires you to use your upper body differently.

I was doing some weights work when I had the controls fitted, so I was moderately fit. However, I still found using my upper body to drive quite tiring. They require reasonable strength in the upper (left) arm for steering, especially long slow curves to the right. You will be using your middle and upper back muscles and shoulders, as well as arms. The right arm will be used for both your brake and accelerator pedals.

Your non-disable driver/s will be able to use the car, but need to remember to move their foot around the linkage rod for the brake.

Requirements by RTA: Driving Test: You will be required to do a driving test with your controls. A little practice in a quiet area before hand is a good idea, as it is a whole new experience. I suggest picking up the car from the engineers about mid morning, when traffic may be light, and a back-up driver to follow you home while you get used to the controls.

Medical: You will be required to have a medical check yearly with your GP, who will then sign the form for you to submit to the RTA.

Freedom: Once you have a suitable car, it does take some time picking the engineering firm, and talking about where the controls are to be situated to feel comfortable for you. DO make sure they are comfortable before you drive off, as they can be further adjusted to suit.

Now you have the safety and freedom to go anywhere!

Hand controls allowed me to be involved with CMTAA, and volunteer for 20 years or so. It allowed me to work, be in business with my husband, take off on weekends with my girlfriends, go to university in my 40's, do computer classes in my 50's and still be getting out and about in my 60's. I always loved driving and still do.

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We provide our clients with:

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- recommendations and treatment plans for footwear/orthotics
- solutions to problems other practitioners could not find

"I couldn't walk unassisted until I got shoes from Ernie." J.C.

For more information see our websites or give us a call



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WESTERN AUSTRALIA

Hi everyone,

The Western Australian support group benefited from meeting with Dr Scott Denton on Saturday 20 June with 24 of our members attending. It was a rare opportunity to meet with Dr Denton, being someone who is living with CMT, as well as being an experienced research fellow at the University of Sydney conducting the national survey into CMT.

The meeting was very well received by all those who attended, who benefited from sharing their personal experiences and living aids (e.g. computer dictation software, dressing aids, etc), as well as hearing about similar and varying impacts of CMT on other people elsewhere in Australia. Dr Denton was also able to travel and meet with a number of our members living in regional Western Australia who were unable to attend the meeting in Perth. We're looking forward to hearing about the results of Dr Scott's survey and its impact on continuing to raising the awareness of CMT within federal and state/territory governments, in addition to the broader community.

We're now planning our next meeting, scheduled for Saturday 15 August 2015 from 2:00-5:00pm at the Genetic & Rare Disease Network (GaRDN) office, 37 Hampden Road, Nedlands. At this meeting we'll be welcoming Mr Laurie Foley (Dip Ch. Grad Dip (HLthSci) MSc, F.A.Pod.A. F.A.W.M.A), A/Professor Podiatric Medicine from the School of Surgery, The University of WA who runs the UWA Podiatry Clinic. The presentation will include how the clinic can assist our members with organising foot orthoses and customised shoes, often covered by government funding.

Once again, we do hope you'll be able to join us and support the committee who organise the meetings!!!

Regards CMT WA Committee

HANDY HINT

‘I had to change to carbon fibre AFOs as the plastic ones kept breaking. They are much harder and were rubbing my feet and legs, so I lined them with lambs wool shoe inserts and taped them in place. Much more comfortable. I also wear 2 pairs of knee high socks; one pair for my feet and one pair over the AFOs to keep them in place.’

Anne Milligan

CMT AUSSIE KIDS WEEKEND

Plans are in their final stages as the forth CMT Aussie Kids Weekend approaches with excitement and anticipation building. This year has seen a dramatic increase in attendees once again, with 25 ‘kids’ coming to the camp at Berry Sport and Recreation Centre on the South Coast of NSW. Attendees will be travelling from most states and territories of Australia. We have again been able to offer all interstate participants travel assistance with their flights as a result of receiving a grant from The Qantas Foundation in 2013 and have also arranged for a shuttle bus from Sydney Airport to transport the ‘kids’ arriving from interstate to camp. We have continued to seek funding for the camp to assist as many kids with CMT in attending the fun weekend and this is an ongoing passion of us both.

The camp will be held from Friday 28th August—Sunday, 30th August 2015 with activities including canoeing/kayaking, rock climbing, an initiative course and cable glide. Kids aged from 9 to 49 (and a little bit over if you push us) will be joining in this year with adult volunteers both with and without CMT. A big thank you to our supporters who have got the word out about the camp and to others for their generous donations specifically for the kids camp. Look out in the next newsletter for a report and photos from the camp.

For more info about this year’s camp or other youth activities please email us at cmtaussiekids@gmail.com

Jillian and Peter Critchley. Organisers CMT Aussie Kids Weekend

CMT AWARENESS MONTH

Plans are well underway for the CMT Awareness Month in September, a month dedicated to spreading awareness and knowledge about CMT. Organisations dedicated to spreading the word about CMT around the world, including CMTAA will celebrate and educate their local and global community of the needs of people with CMT. CMTA (America) and CMTUK (Britain) are just some of the worldwide CMT organisations joining with us in the month of celebrations.

WHAT ARE YOU DOING TO SPREAD THE WORD??

OUR SATURDAY CONSTITUTIONAL

Those of you who have been members for a while will have experienced significant improvements over recent years in the way CMTAA now operates and interacts with its members and the broader community. We are taking advantage of the latest technology for as many of our services as possible to improve our efficiency, which is vital given the small number of volunteers on the Committee. Now we have a clearer picture of how a modern association should operate, your committee has realised that the rules by which we conduct our business include some anomalies when compared with this best practice.

CMTAA is an incorporated association in NSW and therefore is bound by that State's 'Associations Incorporation Act 2009'. The other document which sets the rules by which we operate is our Constitution. Since the current Constitution was drafted in 1990, the legislation has changed, as has the way we are now able to manage our finances and communicate with you our members. As a result your committee has been working on an update, and we are now ready to seek your support for its adoption.

With the introduction of the 2009 Act, a set of 'model rules' were developed to make it easier for new associations to develop their constitutions to align with the requirements of the Act. Your committee has decided that the best approach is to adopt this model as the basis for a revised Constitution, with minor variations to fit our operating procedures. Having achieved this, we will then seek your support for this new Constitution as a full replacement for our current one.

Managing this sort of change is complex, as the wording of each clause needs to be carefully considered to align with legislative requirements, but also meet our specific requirements. Our objective has also been to vary as little as possible from our current constitution. For this reason we have decided not to present you with this complexity, but rather to present you with a simple choice to accept or reject the whole document. This will be done through a special resolution at a Special General Meeting (SGM) to be held before our AGM on Saturday 12th September, prior to our Sydney Seminar on the Sunday.

For those of you who wish to get into the detail of the changes we will be posting both the old and proposed new Constitutions on our website. If you have difficulty accessing the documents this way then we will print a copy and post it to you; however given that this will involve over 20 pages we do ask that you use the web version if you can.

For those unable to attend the SGM we will be circulating a proxy voting form with the notices of the SGM and the AGM. The resolution to adopt the new constitution needs to be a 'special resolution' and as such this will require a 75% approval by those voting, either at the meeting or by proxy. Your committee has given this change considerable thought and we are confident that this new constitution will see us well placed to manage your association for some time to come without further changes. We look forward to your support when you are asked to vote.

Your Committee

STATE COORDINATORS

NATIONAL OFFICE—SYDNEY

Phone: (02) 9767 5105 Fax: (02) 9767 5167

Email: cmtaa@email.cs.nsw.gov.au Website: www.cmt.org.au

AUSTRALIAN CAPITAL TERRITORY

Mrs. Gabrielle Evans
Phone: 02 6288 7235
Email: gabriellecmt@gmail.com

QUEENSLAND

Position vacant

VICTORIA

Jenny Dickson
Mobile: 0428080070
Email: jenny.dickson71@hotmail.com

SOUTH AUSTRALIA

Mrs. Antonia Karydis-Frisan
Phone: 08 8152 0801
Mobile: 0416 051 438
Email: antoniakfcmt@gmail.com

NORTHERN TERRITORY

Mrs. Kaye Bartlett
Phone: 08 8985 4201
Email: kayeCMT@iinet.net.au

WESTERN AUSTRALIA

Mrs. Angela Corfe
Mobile: 0414 905 013
Email: angelacorfe@hotmail.com

TASMANIA

Mrs. Marilyn Kremmer
Phone: 03 6239 1142
Email: mmkremmer1@bigpond.com

NEW ZEALAND

Vacant

SUPPORT GROUP COORDINATORS

NEW SOUTH WALES

Sydney Western Suburbs

Mrs. Carmen Frendo
Mobile: 0404 848 076
Email: carmbutch@gmail.com

Newcastle

Mrs. Gabby Cosgrove
Mobile: 0412 891 647
Email: gabbypizzingrilli@hotmail.com

Wagga Wagga

Mrs. Jean Purvis
Mobile: 0402 535 692
Phone: 02 6931 4635
Email: jeanpcmt3@gmail.com

Central Tablelands

Mrs. Sue Hardy
Mobile: 0412 992 665
Phone: 02 4757 3892
Email: sue@wentylfalls.com

Nambucca Heads

Mrs. Meryl Grew
Mobile: 0428 764 686
Phone: 02 6568 5038
Email: merrynow@bigpond.com

Illawarra District

Ms Tracey Lee
Phone: 02 4272 4404

Mudgee District

Mrs. Ann Milligan
Mobile: 0450 737 563

Central Northern District

Mrs. Judy Gill
Phone: 02 6769 3122
Mobile: 0428 439 434
Email: Judyagill1708@yahoo.com.au

SUPPORT GROUP COORDINATORS (continued)

AUSTRALIAN CAPITAL TERRITORY

Canberra and District

Mrs. Gabrielle Evans (See above)

QUEENSLAND

Brisbane

Mr. Stephen Bonner

Phone: 07 3324 2972

Mobile: 0404 688 824

Email: stephencmt@iinet.net.au

Gold Coast

Mrs. Judy Pinchin

Phone: 07 5563 8421

Email: judithpinchin@bigpond.com

Sunshine Coast

Mrs. Aileen Harrison

Phone: 07 5309 6362

Mobile: 0400 372 640

Email: aileen_advice@optusnet.com.au

South East District

Mrs. Kym Kruger

Mobile: 0408 797 963

Email: kymbilly1@hotmail.com

South West District

Mrs. Joy Gath

Phone: 07 4668 9009

Email: joygath67@gmail.com

South Brisbane Area

Mr Graeme Kendall

Mobile: 0403 801 343

Email: gnkendall@iinet.net.au

Townsville and District

Mrs. Jessika Wathen

Mobile: 0421 064 230

Email: jess_wathen@hotmail.com

Bundaberg and District

Mr. Hadley Cooper

Email: hadmargy@gmail.com

Home: 07- 4152 3122

Mobile: 0427 723 122

TASMANIA

Hobart and District

Mrs. Marilyn Kremmer (See above)

WESTERN AUSTRALIA

Perth

Mrs. Angela Corfe (See above)

Mr. Chris Murphy

Mobile: 0407 214 250

Email: chris_murphy@iinet.net.au

VICTORIA

Melbourne

Jenny Dickson

Mobile: 0428080070

Email: CMTJenny@outlook.com

Mrs. Katherine Robins

Mobile: 0407 114 380

Email: kathy@blanketsecurity.com.au

Bendigo and District

Mrs. Heather Anderson

Phone: 03 5439 3774

SOUTH AUSTRALIA

Adelaide West

Mrs. Antonia Karydis-Frisan (See above)

Adelaide North

Mrs. Lisa Moore

Phone: 08 8254 8744

Mobile: 0459 084 437

Email: cmtlisam@gmail.com

East Adelaide

Dr Andrea Pollock

Mobile: 0414 604 258

Email: CMT.East.Adelaide@gmail.com

NORTHERN TERRITORY

Darwin

Mrs. Kaye Bartlett (See above)

NEW ZEALAND

Vacant

THANK YOU for donations from 1st April 2015—15th July 2015

\$500 and over

In Memory of Mrs. Katherine Douglas	Mr. Neil Donaldson	Mrs. Margaret Vermeesch
Mrs. L. Hughes	Mrs. Dorothy Libbesson of Guardian Interlock Ltd.	

\$200 - \$499

Mrs. M. Finch	Mrs. Annette Roberts	Chiltern Lions Club	Mr. James Christou
Mr. Russell Holmith	Mrs. Margaret Ericson		

\$100 - \$199

Mr. Roger MacRury	Mrs. Anne Leggett	Mr. John Levy	Mr. J. M. Kuras
Dr. Andrew Wines	Mrs. Benita Robbie	Mrs. Margaret Rogers	

\$50 - \$99

Mr. John Collis	Mrs. Denise Eastwood	Mrs. Betty Smith	Mr. George Germantse
Mrs. Julie Rowe	Mr. Christopher Sewell	Mrs. Barbara Deius	Mrs. Gaile Fornusek
Mr. Michael Fitzpatrick	Mr. Robert Twin	Ms. Christine Kelsall	Mr. Mark Bainbridge
Mrs. V. Gravel	In Memory of Carlo de Nardi		

\$20 - \$49

Mrs. Marilyn Rowlands	Mr. Stephen Stokeld	Mr. Ernie Tye	Mrs. Ann Milligan
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\$1 - \$19

Ms. Lynda Brook	Mr. Edward Ivey	Mr. Barry Brown	Mrs. Annette Maie
Mr. Richard Seymour	Mr. Stephen Patterson	Mrs. Patricia McGee	

DONATE TO CMTAA

Please follow the steps below to donate to the CMTAA:

Step 1: 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

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.

SYDNEY CMT AWARENESS WEEKEND

SATURDAY, SEPTEMBER 12th and SUNDAY, 13th, 2015

Venue: Building B26, Concord Medical Education Centre, entrance Gate 3, Hospital Rd., Concord Hospital, CONCORD NSW

Time: Saturday 12th: SGM and AGM, Mix and Mingle and Open Forum:
2pm to 5pm

Sunday 13th: Awareness Seminar: 9.00am to 3.30pm.

Speakers: Professor Garth Nicholson, Dr. Manoj Menezes, Professor Joshua Burns, Dr Scott Denton, Dr. Alison Shield, CMT Aussie Kids plus interviews with people with CMT.

Topics: CMT Research, CMT in Childhood – Trials and Interventions, CMT Survey Feedback, Medication and CMT Focus Groups, A Workshop on “I Have CMT – What Happens Next?”

Cost: Saturday 12th: SGM & AGM - Mix and Mingle & Open Forum (including light refreshments): **FREE**

Cost: Sunday 13th: Awareness Day Seminar: Adults: \$35 per person, \$10 per child under 18 years and \$80 per family (2 adults and their dependent children under 18 years). This includes an attendee kit, morning tea, lunch and light refreshments.

Parking is conveniently available in the hospital car park opposite the entrance to the Concord Medical Education Centre. Concession parking cards will be available when registering to enable you to park all day for \$5 which is payable when exiting the car park. Disabled parking is available directly in front of the Concord Medical Education Centre. Just drive through Gate 3.

Please register your attendance through the Seminar RSVP link at the end of the Sydney Awareness Day Seminar article on the CMTAA website, by filling out the section below and sending back to the office address above or by emailing or phoning the National Office on 02 9767 5105 **by September 9th** together with your attendance fee. Alternatively, please call our National Office on 02- 9767 5105 to register your attendance and pay on the day.

A Certificate of Attendance for professional development will be available if required.

Name/s:

Number attending:Email:

Address:.....

Amount enclosed: \$ Telephone contact number:

I/We will be attending the **SGM/AGM and Mix & Mingle on Saturday, 12th September, 2015** : Yes: No:

I/We will be attending the **Awareness Seminar on Sunday, 13th September, 2015**: Yes:No:.....

CMTAA COMMITTEE (2013/2014)

Executive Members

President:	Darryl Beitsch (NSW)
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Jillian Critchley (NSW)

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Joanne Liso (NSW)

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Louise and Will Battaglione (Qld)

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 October 2015

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)

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Charcot-Marie-Tooth Association of Australia Inc.

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

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