

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 74 Spring 2013



CMTAA

Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

Antwerp CMT Consortium



Darryl Beitsch, our CMTAA President recently had the opportunity to attend the **5th International CMT Consortium** meeting in Antwerp, Belgium. Darryl reports: "This is where leading CMT researchers from around the world share their findings from the very wide and varied range of CMT related research projects that they have been working on. Every year we are a step closer to the solution. I was greatly encouraged by their commitment, passion and dedication. A lot of the presentations included video of rats and mice that were key research subjects. If you think we look funny with our 2 legged gait, you should see these subjects with 4 legs! This is a very important part in the long road to resolving CMT.

What was of great interest was the opportunity to meet with the leaders of support group organisations from other countries. These included USA, UK, France, Italy, The Netherlands, Switzerland, Spain, Belgium and Australia. We all have so much in common – how best to support our members as they live with and manage their CMT and how best to support our Researchers, Medical and Allied professionals. This also opens the door for more International co-operation and exchanging of ideas".

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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



Winter is now here and for those of us living in the cooler areas of our nation this time of the year can impact our CMT. However, we have to remain strong and I encourage you to work through the situation. I have found that an electric blanket makes all the difference in providing a nice warm bed that quickly thaws out the cold legs ensuring a good night's rest.

New Logo

As you have noticed, we now have a new logo. Your CMTAA Committee believes that it is now the appropriate time to move forward with a new logo and a significant website upgrade. The new website will soon be commissioned, however, we would appreciate your patience as it takes time to ensure that everything is the way we want it to be. The new site will also include links to Facebook and Twitter.

Support Groups

We have been promoting the importance of Support Groups – a venue where people with CMT can come together to share with and encourage one another in an understanding environment. This year Support Groups have been meeting in Tasmania (including a seminar), WA (including a seminar), ACT and the Gold Coast. There is a seminar planned for Victoria in November as well as other Support Group meetings that are still being finalised.

Clinical Trial Volunteers

1. Held at the Children's Hospital at Westmead in Sydney involving 60 children aged 6-17 years who will be randomly allocated to one of two strength training intervention groups. The investigators hope this treatment will provide a solution to weakness, disability, deformity and poor quality of life in children with CMT. Please see the article in this newsletter for more information.

2. Held at the University of Sydney Faculty of Health Sciences, Lidcombe campus, this study is testing the effect of shoes and customized shoe inserts on balance and walking stability in adults with CMT. Please see the article in this newsletter for more information.

Held at the University of Sydney Faculty of Health Sciences, Lidcombe campus, a pilot trial study is being developed that will provide information regarding the effectiveness of Progressive Resistance Training for people with CMT. Titled "Exercise to Enhance Functionality". This will involve 10 sedentary people with CMT Type 1 and X Linked aged 18 to 60 years.

Please contact our CMTAA National Office on 9767 5105 if you are willing to participate in one of these trials.

Student Assessment Volunteers

If you are interested in being a real live "CMT Patient" to assist in student assessments and are available on 1 or more of the following dates, please contact our CMTAA National Office on 9767 5105. The venue is the University of Sydney Faculty of Health Sciences, Lidcombe campus. Details are:

Monday 2nd September 1-3pm

Tuesday 10th September 10am-12pm

Parking will be organized. Participants will undergo an exercise session including instruction on how to perform relevant exercises to enhance functionality and a series of assessments.

September CMT Awareness Month

We will have available an international theme logo poster if you can assist to distribute in your area. Please contact our CMTAA National Office on 02m 9767 5105 if you can assist with this.

Sydney Awareness Day Seminar

Don't forget that the Sydney Awareness Day Seminar is Saturday 12 and Sunday October 13. Please see the detailed advertisement in this newsletter.

As you can appreciate, there has been a lot happening. We are growing and evolving thanks to the many dedicated volunteers who, over the years, have all contributed to your CMTAA. Through their commitment, we have in place a strong foundation that we are now in a position to build upon. Please note that to continue to grow we need volunteers throughout Australia and locally. If you believe that you have time and expertise, please call our National Office on 02 9767 5105 so that we can have a chat. Take care and keep moving.

NEWS FROM THE STATES

WESTERN AUSTRALIA

Thanks to all who attended our last meeting held at Rocky Bay, especially our new members. The venue was great and Liana, our host provided us with lots of information about the organisation and services provided. We had a great opportunity to have a look around, particularly at the gym facilities which were 'wheelchair friendly'. Hopefully, we'll have an opportunity in the future to use the venue again and perhaps even have a workout in the gym!!

We were hoping the venue would attract our younger members as we're still unsure how many of our members have children diagnosed with CMT - so please get in touch if you want to contact other families in WA.

So far this year we've held two meetings but the committee is open to members input/ideas for future meetings, so please contact us if you have idea for new presenters or you'd like us to invite previous presenters back.

Will be in touch with members in the near future with information on our next meeting.

Kind regards, WA CMT Committee



TASMANIA

Tasmanian CMT Awareness Day

What a great turnout we had for our Tassie Awareness Day with approximately 50 folk attending. Following a story in our local paper I had 20 phone calls in 2 days so we've got lots of new faces in our Support Group now! We also had 7 physiotherapists attending which was good – unfortunately no-one from the medical profession despite lots of advertising in the Medical School. However our speakers, Phil Ladlow, physiotherapist, Associate Professor Josh Burns, Dr Eppie Yui Paediatric Neurologist, and Ben Curry, Podiatrist impressed all the participants. I had my fingers crossed that Josh and Eppie's planes would arrive on time and they did, especially as fog had delayed flights the previous 2 days. The “plane gods” were kind to us!! We started at 10am and went through to 3pm with short stops for lunch and morning tea (so much food!!!) My dear neighbours and friends, knowing that I had a sick grandchild having surgery in Melbourne, rallied round with plates of food as well our local support group folk – I think everyone went home with a plate of food! We also had quite a few donations which enabled us to keep the cost of registration down. It was a lot of hard work but so very satisfying to see folk go home much more informed and more comfortable with their condition knowing there was an Association and Support Group looking after them!!

Marilyn Kremmer, Tasmanian Co-ordinator.

Marilyn, Associate Professor Josh Burns and Dr Eppie Yui at the highly successful Tasmanian CMT Awareness Day



GOLD COAST

Hi Judy from the Gold Coast here, hoping you are all keeping warm and dry, all I can say is roll on Spring! As we had a great coffee morning at Pacific Fair, I'm hoping that we can have a few more meetings like that. We are trying to organise a Seminar in Brisbane early next year, there will be more information on that as it comes to hand. As Albert Wright, Glenda Smart and Malcolm Shorthouse have all spent time in hospital lately, I would like to wish them all the best. I'm looking forward to catching up with members of our C.M.T family, and making some new friends when I come down to Sydney for the Seminar. I would like to say how great the Facebook page is! Well until next time, take care, and remember, "KEEP SMILING" Judy.

VICTORIA

Hi Beautiful people,

I would like to introduce myself. My name is Nelly Sutjipto, I am a 28 year old mother to two gorgeous children, a wife to my amazing supportive husband and I have CMT type 1A. I have been affected since a very young age. As most of us do I was told by countless doctors what I could NOT do in life as a result of my CMT. I was bullied at school for being different, I felt alone and like nobody understood me or my CMT. I tried ever so hard to always do what everybody else did but it usually resulted in falls, pain or injury. There have been times where I felt ashamed, embarrassed and would walk the streets with my head down low. Over the years with the help of my husband I have come to realise that my CMT is nothing to be ashamed of. That I CAN do many things if only I believe in myself. It wasn't until the recent births of my children in the last two years that I really gained my inner roar! Having had two very different experiences I gained such knowledge, strength and courage that now....I feel unstoppable! With both pregnancies and deliveries came pain and struggle, trips and falls and countless questions by doctors: so what is CMT. I went on to prove to the doctors that always said I may not carry full term, may be bed bound and will be unable to birth naturally wrong. I did everything they said I would not be able to do. I have always wanted to reach out to others with CMT, to let everyone know that we are BEAUTIFUL. We are courageous and strong and powerful. We display enormous strength each and every day that we battle CMT. Together if we Unite and celebrate our differences and embrace our uniqueness then I believe we are unstoppable! I have a Facebook support group with members from Australia and all over the world www.facebook.com/groups/Cmtunitesus

I will also be starting a support group for anyone in Melbourne. If there is anyone that wishes to speak with me about my experience, wants to hear my pregnancy and birth journey and ask questions or how I cope with two little ones and CMT please feel free to contact me.

Please contact me on my email: nellycmt@gmail.com

Love to you all. You are all strong, amazing and beautiful. Believe this each and every day!

Nelly Sutjipto

Editor's note: See Page 9 of this newsletter for details of the next Victorian CMT Seminar in November . Nelly is now our CMTAA coordinator for Victoria and also our CMT Support Group coordinator for Melbourne. Nelly is supported by Janeene Payne. Janeene can be contacted on 0413279087 or paynejaneene@gmail.com

SOUTH AUSTRALIA

Hi this is Antonia from SA. This is my first contribution to the newsletter and would like to encourage those in good Old SA (some 14 of you!) that you are not forgotten. Firstly on an official basis I would like to take the opportunity to sincerely thank our past coordinator Mrs Lumsden for all her efforts.

Briefly, my involvement with CMTAA Incorporated first commenced as a member in 2007 and came about after our daughter was diagnosed with CMTA Type 1A. My involvement with CMTAA also over the past four years has been as a CMTAA committee member. As a member and committee member my family I and have found immense support and encouragement from the CMTAA community activities at large and especially the CMTAA committee. The knowledge gained and experiences shared from my exposure and association with the CMTAA community has enabled my daughter and our family to move forward with the disease of CMT and live life to the fullest. As SA coordinator over the years I have fielded a number of calls and emails from various age groups and from many diverse walks of life. I have very much enjoyed and found challenging the work as a committee member and have gained much strength and motivation from my colleagues on the CMTAA committee. Given my association with CMTAA, I have now reached a stage that I am ready to take a more direct role in sharing the benefits of becoming involved with the CMTAA community and seek local support, because with numbers comes strength. I am happy to discuss the particular benefits and exciting developments about becoming a CMTAA member and invite you to call me to discuss further.

Therefore, on behalf of the SA membership I would like to commence and provide regular contributions to the newsletter. In this way we not only confirm our presence and raise awareness of CMT in SA but lend support nationally to CMTAA with their endeavours. As in the other states my colleagues have many activities on offer within their regions addressing CMTA issues and I would like to propose that we offer similar opportunities in SA as well as feel more connected to CMTAA.

Initially, I would like to extend an invitation to all SA readers (including non-members) to contact me and express their interests and views about holding a seminar or a get together. To kick off, I take the liberty of proposing the following dates for a get together being either: Sunday 29 September 2013, Sunday 27 October 2013 or Sunday 30 November 2013 and suggest an afternoon between 2-5pm with light refreshments. Depending on access requirements and of course numbers I am happy to initially offer my home as the venue or hire a venue or book a cafe. In addition to this newsletter notification, I intend to forward a general newsletter advising of the planned event and warmly open the greet and meet to non-members.

An acknowledgement

On a closing note given that my daughter (nearing adult hood) has to transition from the youth medical treatment providers I would like to share and acknowledge our gratitude for all the support and assistance we have been provided by the Women's and Children's Hospital in particular Dr Ray Russo and Dr Damian Clarke and to Novita Children's Services in particular to Prithy Robinson and Alison Firth who together with their extensive support teams have assisted our family to meet the daily challenges of CMT.

To all the SA readers we look forward to hearing from you soon about the get together or if you would like to place an item in the newsletter.

Kind regards. Antonia

08 81520801

antoniakfcmt@gmail.com

Spread the word about CMT

CMTAA 2013 SYDNEY

CMT

AWARENESS DAY AND SEMINAR

THIS YEARS AWARENESS DAY AND SEMINAR WILL BE HELD ON THE
12TH AND 13TH OCTOBER AT THE NEW AND EXCITING VENUE THE
CONCORD MEDICAL EDUCATION CENTRE, BUILDING B26 CONCORD
HOSPITAL

SATURDAY THE 12TH FROM 3PM – 5PM . AGM FOLLOWED BY LIGHT
REFRESHMENTS AND AN OPPORTUNITY MIX AND MINGLE.

SUNDAY 9.00AM TO 3.00PM. LEADING PRESENTERS WILL COVER
CMT RESEARCH; MANAGEMENT OF CMT; GENERAL
PRINCIPLES REGARDING MEDICATION AND CMT; USEFUL AIDS FOR
IMPROVED QUALITY OF LIFE; PLUS BREAKOUT
SESSIONS INCLUDING "HINTS FOR PARENTING CHILDREN WITH
CMT FROM PRE-SCHOOL THROUGH TO TRANSITION TO
TERTIARY EDUCATION/WORK FORCE"; "STRATEGIES TO FACE THE
CHALLENGES OF CMT AS WE GET OLDER"; Q & A
SESSION WITH OUR EXPERTS PLUS INSPIRING INTERVIEWS.



INCLUDED IS AN ATTENDEE PACK, MORNING TEA AND LUNCH.
COST \$30 PER ADULT; \$10 PER CHILD UNDER 18 YRS; \$70
FAMILIES (PARENTS AND THEIR CHILDREN ONLY) PLEASE
REGISTER YOUR ATTENDANCE BY PHONING 02 9767 5105 OR
EMAIL: CMTAA@EMAIL.CS.NSW.GOV.AU
BOOKINGS ARE ESSENTIAL

Foot and Ankle Strength Training for Charcot-Marie-Tooth Disease (CMT)



A major problem for children with CMT is foot weakness. Currently there are no effective treatments for this problem. Strength training might be beneficial, but is untested in CMT.

We are performing a study at The Children's Hospital at Westmead (Sydney) looking at the effect of foot and ankle strength training in **children with CMT aged 6 - 17 years**.

If you have a child with CMT or know of any children with CMT who might be interested in this clinical trial, please contact the investigators:

Associate Professor Joshua Burns and Dr Amy Sman

Institute for Neuromuscular Research,

The Children's Hospital at Westmead, Sydney

Phone: (02) 9845 3004 or Email: amy.sman@health.nsw.gov.au

We will be able provide reimbursement of up to \$10 per visit for travel expenses to The Children's Hospital at Westmead. This clinical trial has been approved by The Sydney Children's Hospital Network Human Research Ethics Committee at The Children's Hospital at Westmead (Sydney) under approval number 13/SCHN/21.





CMTAA IS NOW ON FACEBOOK AND TWITTER

Search: <https://www.facebook.com/pages/CMTAA/604686846216785?fref=ts>

Or log onto Facebook and search 'CMTAA'

And <https://twitter.com/CMTAA>

Or log onto Twitter and search @CMTAA

BEAUTIFUL CMT JEWELLERY AVAILABLE

We have recently been contacted here at CMTAA by a member to say that a friend of hers from Krystal Creations has made these and other beautiful pieces available for sale, with 20% of the profit being donated to CMTAA. You can find her work on Facebook at

<https://www.facebook.com/pages/Krystal-Creations/213162455399904?ref=ts&fref=ts>

or by searching eBay with the links below:

http://www.ebay.com.au/itm/CMT-Awareness-Stretch-Sky-Blue-AB-Faceted-Crystal-Hope-Charm-Bracelet-/321161756732?pt=AU_FashionJewellery&hash=item4ac6bb803c&_uhb=1

http://www.ebay.com.au/itm/CMT-Awareness-Blue-European-Charm-Bead-Bangle-Ladies-Girls-/321161749380?pt=AU_FashionJewellery&hash=item4ac6bb6384&_uhb=1

http://www.ebay.com.au/itm/CMT-Awareness-European-Charm-Keyring-/321161762459?pt=AU_FashionJewellery&hash=item4ac6bb969b&_uhb=1



<http://www.ebay.com.au/itm/CMT-Awareness-Blue-European-Charm-Bead-Bracelet-Ladies-Girls-/321161743204?>



CMT NEWS

RESEARCH STUDY

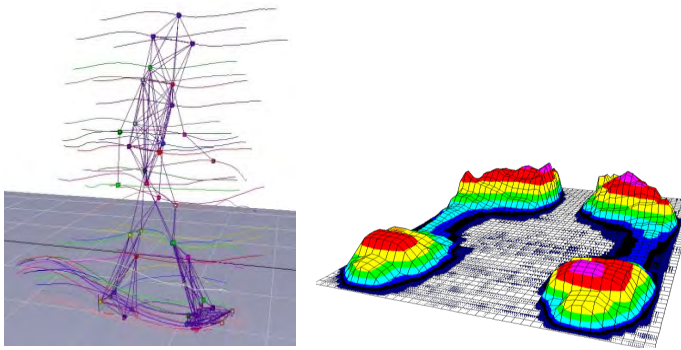
Volunteers needed for a study on shoes and shoe inserts for adults with CMT

This study is testing the effect of shoes and shoe inserts on balance and walking stability in adults with CMT.

You are invited to participate if you are aged **18 to 70 years**, **not currently** using **ankle foot orthoses** (splints) (AFO's) and **not** had **previous bone or joint surgery on the foot or ankle**.

The study is coordinated by podiatrist and researcher Mr Caleb Wegener and his colleagues at The University of Sydney.

Volunteers will be required to attend The University of Sydney, Cumberland Campus (Lidcombe) on three occasions, the first visit for 1½ hours and subsequent visits for 2½ hours. During the second and third visits participants will be asked to walk and stand in three shoe/shoe-insert conditions. High-tech 3D motion capture technology, similar to that used for in 3D animation in movies, will be used to measure foot and leg motion.



If you are interested in volunteering for the study, please contact podiatry researcher

Caleb Wegener on 02 9351 9403 or email caleb.wegener@sydney.edu.au.

Participation in this study is entirely voluntary. You are not obliged to participate, and if you do, you may withdraw at any time without reason or prejudice.

VICTORIAN SEMINAR

Victoria CMT conference day is booked for **Sunday November 24**. The day will commence 2pm sharp at the **Heidelberg Repatriation Hospital** in the HRH wattle room. This years conference will be an excellent opportunity to gather information, stay informed about local services and support and most importantly spend the afternoon in the company of fellow CMT friends.

The cost of the day is \$10 per person and \$20 per family. Please contact Nelly via email nellycmt@gmail.com for further information and to confirm your attendance.

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.

Here are some ways that you can get involved:

- ⇒ Displaying CMT brochures, posters and newsletters at libraries, pharmacies, doctors surgeries, workplaces and hospitals.
- ⇒ Sending a story about you and CMT to your local newspaper/radio station.
- ⇒ Filming videos that show how CMT effects you or family members to post on YouTube. Substituting the CMTAA logo for your profile picture on social networking sites.
- ⇒ If you have children with CMT why not visit their school and talk to an assembly, teacher's professional development day, or just in the classroom about how CMT impacts lives. One of our Area Coordinators Aileen Harrison has been doing just this and getting a great response.
- ⇒ Talk to your friends , family and workmates—they may know nothing of the daily challenges you face and letting them know how they can help.



Below is a quick list of key points that are useful when trying to tell people about CMT. Charcot-Marie-Tooth disease (CMT) is a hereditary (genetic) condition that damages the peripheral nerves. These nerves are responsible for passing on commands from the brain to the muscles in the arms and legs, and for passing information back to the brain about sensation - pain, heat, cold and touch.

Other key points are:

- * causes the muscles in the legs and arms to waste, which can cause problems with walking, standing and balance and difficulties with hand function and strength
- * feet can become deformed, with high arches, curled toes and very weakened ankles
- * can cause numbness and poor sensation in the lower legs and arms
- * can cause chronic pain and fatigue
- * is slowly progressive, worsening over time
- * severity differs, even within the same family
- * is not curable but can be managed with assistance
- * affects all ages, genders and ethnic groups

Have a great Awareness Month, Janeene Payne CMT Awareness Month Coordinator; Jillian Critchley

Experience the products and service of a team who understand Charcot-Marie-Tooth disease.



- Professionally sized and fitted
- Wide range of extra depth footwear
- Quality crafted products sensitive to your specific needs
- Extensive options to fit an AFO

Exclusive global brands
working with CMT



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Has your organisation considered becoming a Sustaining Partner of CMTAA?

Through its Sustaining Partnership Program CMTAA provides opportunities for organisations which support its objectives to partner CMTAA through an annual financial contribution. In return CMTAA will help your organisation promote its objectives and receive acknowledgement for its support of CMTAA.

There are two levels of Sustaining Partnership to suit the varying needs of organisations.

As a **Silver Sustaining Partner** your organisation will receive recognition through a framed certificate; acknowledgement in the CMTAA Annual Report; your logo with a link to your web site on the CMTAA web site; recognition of your organisation's support at CMTAA events held around Australia and in the newsletter; permission to use the CMTAA logo to advertise your partnership; promotion of your events through the CMTAA network; and a complimentary membership of CMTAA.

As a **Gold Sustaining Partner** (only 5 available) your organisation will receive all of the above plus complimentary advertising in the CMTAA newsletter and acknowledgement on the front page of the CMTAA Newsletter and CMTAA home page.

The potential exists to negotiate variations to these packages through part in-kind support.

If your organisation would like to participate in this program then please contact either Darryl Beitsch (President) or Robert Twin (Treasurer) through the CMTAA Office.

THANK YOU for donations from 1st April—25th July 2013

\$5000 donation received by G Building Products Ltd

\$1000 donation received by James and Bev Galloway

\$500 and over

James and Bev Galloway	Valerie Adlam	Mr Adam Jeffrey	Anon
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\$200—\$499

Mr Raymond Banting	Mr Geoffrey Docker	Mr James Christou	D Clancy
Mrs Marion Ericson	P Hughes	L Hughes	

\$100—\$199

Mrs Annette Roberts	Mrs Helen Purcell	Dr Andrew Wines	M Finch
Mr John Etchells	Mr Ken Nicholson	Mrs E Nielson	M Rogers
Ms Carolyn McKay	Christine Kiem	Inner Wheel Club of Clarence	

\$50—\$99

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Mrs Helen Hickey	Mrs Barbara Higgins	Ms Janis Floyd
Mr Mark Bainbridge	Mrs Nancy White	Mr Stephen Stokeld
Mr and Mrs John Boyle	Mrs Barbara Deuis	Mr Larry Triffitt
Mrs Robyn Eaagles	Mr Dennis Simpson	V Garvell
Mrs Beryl Smith	Mr William Millhouse	Mrs Lesley Polmear
Mrs Ida Ellison	Quentin Goldfinch	Marilyn Collins
Gaile Fornusek	Rotary Club of Moonah	

\$20—\$49

Mrs Megan White	Mrs Ann McLaughlin	Sally Nagel	Aileen Harrison
Mrs Eileen Ramage	Miss Annette Maie	Mr Rick Phleger	Mr James Koios

\$1—\$19

Helen Ward	Mrs Eileen Fogarty	Mr John Collis	Leah Speziali
Mr George Germantse	Mr Barry Brown	Mrs Louise Lupton	Linda Garbett
Ms Sheryl Robertson	Mrs Margaret Psaltis	Mrs Celia Ravesi	Mr E Ivey
Mr Stephen Patterson	Mrs Carol Newman		

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.

CMTAA Committee (2012/2013)

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Treasurer:	Robert Twin (ACT)
Secretary:	Anycie Berkmann (NSW)

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Katherine Matthews (Vic)	
Joanne Liso (NSW)	



SEMINAR DVD's & VIDEOTAPES

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 Aveue, Engadine 2233 N.S.W. or email: cmtaa@email.cs.nsw.gov.au

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Charcot-Marie-Tooth Association of Australia Inc.

The Association is incorporated in NSW and a registered charity (No.CC28099) ARB No. 076 189 912 ABN No. 63076 189 912

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

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A.C.T

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Email: gabriellecmt@gmail.com

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NORTHERN TERRITORY

Darwin: Kaye Bartlett 8 Sunset Drive, Coconut Grove 0810 (08) 89854201 Email: tabncurly@iinet.net.au

NEW ZEALAND

Gaile Fornusek: 07 8686375 Email: fornuskova10@gmail.com

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.

Deadline for next newsletter: 31st October 2013

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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

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

THE CMTAA COMMITTEE WISH TO ADVISE THAT AFTER MUCH DISCUSSION WE HAVE DECIDED TO DISCONTINUE LISTING IN THIS NEWSLETTER THOSE DRUGS THAT MAY AGGRAVATE OR EXACERBATE CHARCOT MARIE TOOTH. WE SUGGEST YOU SPEAK TO YOUR MEDICAL PHYSICIAN FOR ANY FURTHER ADVICE ON THIS MATTER, CONSIDERING YOUR INDIVIDUAL CIRCUMSTANCES.

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

CHEQUE .

KEEP IN TOUCH

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

Address: _____

State: _____

Postcode: _____ **Phone:** () _____

Email: _____

Signature: _____ **Date:** _____

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