

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 73 Autumn 2013

The CMT CoMmuniTy



CMTAA

Charcot-Marie-Tooth Association Australia Inc.

ABN 63 076 189 912

CMT IN PARLIAMENT

Charcot Marie Tooth has certainly been in the headlines over the past few months with Dr Scott Denton, a long time friend, supporter and member of CMTAA being instrumental in the Federal Member for Throsby Mr Stephen Jones moving a motion that the Australian Parliament recognises that CMT is an issue. Our President Mr Darryl Beitsch was present in Federal Parliament on the evening of the announcement, Monday, 26th November, to witness the historic event. This prompted discussions on the national airwaves with CMT being mentioned on radio throughout the country.

The previous week Dr Denton attended a meeting with the Federal Health Minister Tanya Plebersek to discuss issues relating to Charcot Marie Tooth and it's impact on the national economy. Dr Denton's report from The University of New South Wales, the Cost of Charcot-Marie-Tooth Disease on the Australian Economy, states that neurological disorders like CMT accounted for 12 per cent of Australia's disease burden and injury in 2003. A full transcript of the Hansard

report appears on page 4 of this newsletter.



PARLIAMENTARY MEET AND GREET

Top Left **Stephen Jones** MP

Top Right **Associate Professor Joshua Burns** PhD USyd

Bottom Left **Tanya Plebersek** Federal Minister for Health

Bottom Middle **Dr Scott Denton** BA, Hons, PhD UNSW

Bottom Right **Dr Jo Coghlan** BA, Hons, PhD

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

PRESIDENTS REPORT

2013 is now well underway and a lot has been happening. Our second Youth Weekend is booked and as you will see in this edition advertising is well underway. When I called in to last year's Youth Weekend, what impressed me the most was the constant chatter of happy attendees speaking with their new friends. An excellent opportunity to share stories and participate in exciting (and safe) activities that young people with CMT would be unlikely to experience outside of this environment.



Workshops and Seminars

I am greatly encouraged by the workshops and seminars that are scheduled for this year. Our WA friends are leading the charge with 2 workshops, one that has already taken place on March 23 and another taking place on Saturday May 18 which is specifically focusing on families. More information is on our website under "Future Seminars" and in this edition.

Our Sydney Awareness Day Seminar is on Sunday October 13 in the brand new Concord Medical Education Centre located at Concord Hospital. We will have a line-up of quality medical and allied professionals and this year, due to requests from last year's attendees, we will be having 3 "breakout workshops". Stay tuned for more details.

Additionally, at the same venue on the Saturday afternoon October 12, we will be having a "meet and greet" for those who would like to attend. There will be the opportunity to meet your management committee, attend our brief AGM, partake of complimentary light refreshments and have the opportunity to chat with other members of our "CMT Family". Stay tuned for more details.

National Office

We welcome Ann McLaughlin who has volunteered to assist in the office. It is people like Ann that keep us going.

I would also like to thank Carmen Frendo, who due to unforeseen circumstances, has stepped down as an office volunteer and also from your committee. Thank you Carmen for your greatly appreciated contribution to our CMTAA.

Support Groups

We have also been promoting the establishment of more Support Groups throughout Australia and I am pleased to announce that these are slowly taking place. If you are interested in joining a Support Group in your area, please contact the office on 02 9767 5105.

A great source of encouragement for all our office team is to assist people with their many enquiries through the telephone and email. It is a privilege to answer these enquiries with a positive way forward and reassurance that "you are not alone". This is what your CMTAA is all about. Never forget that we all have our special story to tell.

Take care and keep moving.

Darryl Beitsch

President

CMTAA

NEWS FROM THE STATES

TASMANIA

We have been saddened by all the devastation from floods and bushfires that has been occurring in our beautiful country. In Tasmania we have been experiencing the hottest summer on record and although it was good to have the sunny weather for the events that come to Hobart at this time - Sydney-Hobart Yacht Race, Taste of Tasmania and the Wooden Boat Festival - we desperately need rain - it's a pity some of the Queensland rain couldn't get here!! As you know Tasmania experienced some pretty nasty bushfires and as we live on Mount Wellington in bushfire country we have been on alert with our evacuation box sitting by the front door. You can only prepare so much and then mother nature dictates the rest!! We've had a bit of a sad time with two of our grandchildren being hospitalised and with ongoing problems. We did manage to get our week away camping on the beautiful Freycinet Peninsular which was lovely. We've now bought a small caravan and hope to get away for more holidays while we are able!!!

Our little group in Tasmania has been quiet and we haven't had any meeting yet for this year. As soon as I get the DVD of the Awareness Day - we will get together and discuss things. It's great to see things happening in Parliament and that CMT is becoming more known with the number of hits on our website increasing.

Regards, Marilyn Kremmer

GOLD COAST

Hi! Judy here with greetings from the Gold Coast. With the terrible weather, I hope you are all safe and dry.

There are no beaches left open on the coast now. We had get together a little while ago, for a cuppa and a chat. The main topic this time was orthotics, and how to go about accessing them via different options.

I have now settled in back home after having my foot operation, and spending time in respite. I am not doing too badly, considering! The worst part for me because I am so tiny, is that the moon boot that I have to wear weighs nearly as much as me, but it is better than a plaster cast. Also, because of the muscle weakness, I will have to wear it for a bit longer than normal.

Until next time, stay positive, take care, and most importantly, KEEP SMILING! Judy.

WESTERN AUSTRALIA

The CMT WA Branch has started planning for 2013 and will be hosting two events over the next few months which we hope will interest local members.

The first took place on Saturday, 23rd March and was a CMT Information Sharing Workshop at the Genetic Support Council Centre premises in Nedlands. The meeting was very successful with the group first watching a presentation from the National Association's last seminar - Mr Peter Richards on 'How to cope with CMT' - both interesting and motivational. The group then split into smaller groups to discuss a variety of topics and share with others their information with the aim of helping others to manage their day to day lives. It was amazing to discover how much information was exchanged and the committee is planning to put it into a format that can be shared with WA members.

Our second meeting is planned for **Saturday 18th May (2-4pm) – Family Focus Workshop at Rocky Bay, 60 McCabe St, Mosman Park**

This is a workshop for adults and children. A number of our members have discovered that Rocky Bay provides a much needed multidisciplinary approach for people with CMT. You can access their services at any age and you will need to meet their service eligibility criteria. Rocky Bay services adopt a life needs approach. A representative from Rocky Bay will explain the range of services and how you can self refer once you have a diagnosis. We also have children with CMT who are keen to meet other children who might be experiencing similar things to them. Rocky Bay has kindly provided us with an indoor area for children to get together and play or just chat during our workshop. Parent supervision will be required.

We are looking forward to catching up with our regular friends and to welcoming new ones to our group. If you require any further information or to RSVP please contact:

Angela Corfe angelacorfe@hotmail.com 0414 905 013

Chris Murphy chris.murphy@au.knightfrank.com 0407 214 250

CHARCOT MARIE TOOTH IN THE NEWS

HANSARD TRANSCRIPT

Ms GRIERSON (Newcastle) (20:11): I rise to speak in support of the member for Throsby's private member's motion on Charcot-Marie-Tooth disease. I thank the member for Throsby for bringing this matter to the attention of the House. I also welcome his constituents and thank them for taking the time to come to the House tonight. I say to them: this disease is important and you are important, and you have done a very good thing to promote understanding of this illness.

If someone told you that you had this disease and you had never heard of it before, you might assume it had something to do with dental care or dental health, but this is nowhere near the truth. That, however, illustrates the lack of awareness about CMT disease. It is a rather common and yet little understood genetically inherited neurological disorder found around the globe. Its unusual name derives from the three neurologists who discovered the disease in 1886. As the motion states, there is a low level of community awareness about this disease, which is also known as inherited motor and sensory neuropathy, and yet it is in fact the most common form of genetic or inherited neuromuscular disease. Around one in every 2,500 Australians is affected by this disease. Recent international studies have indicated it may be far more common. As the member for Throsby pointed out, because of some of the difficulties in diagnosis, it may be closer to one in 1,000.

CMT is characterised by the progressive degeneration of foot muscles and muscles in the lower leg, hand and forearm, as well as a loss of sensation in limbs and digits. Ninety-five per cent of those with the disease experience weakness in the lower limbs. Whilst not fatal or impacting on life expectancy, it can certainly adversely impact on the quality of life of those with the disease. As life tends to tell us over and over again, we are never able to predict what fate life's deck of cards will deal us. Typically, the first sign is a high-arched foot and problems with walking. Other symptoms include bone abnormalities in the foot and hand grip. It becomes difficult to open bottles and jars and do the basic things like operate taps in the home. It can bring poor balance and tumbles and falls, cramping in the legs and forearms, reflex issues, sight and hearing loss, and, occasionally, scoliosis, or curvature of the spine. This all occurs at a slower rate as the nerves gradually degenerate, making muscles weaker because of a lack of nerve stimulation. Symptoms for this disease appear by the age of 30 in most cases and, of course, that is so young. CMT currently has no cure. This presses the issue and importance of this motion and its aim—to raise awareness of this disease and encourage investment into research into the causes, treatment and preferably a cure. Though it is more common than muscular dystrophy, CMT lacks the community awareness that is often required to bring such issues into the spotlight in order to bring about constructive change and results. Though presently incurable, there are treatment options that do alleviate symptoms, including leg and ankle braces, orthopaedic shoes, physical therapy, muscle training, stretching, low impact exercises and orthopaedic surgery.

But what a regime! Would it not be better, however, to have no symptoms to treat if we could find a cure. The University of New South Wales report, the Cost of Charcot-Marie-Tooth Disease on the Australian Economy, states that neurological disorders like CMT accounted for 12 per cent of Australia's disease burden and injury in 2003. There is limited data on the cost associated, however, to do a direct comparison with muscular dystrophy; in 2005 almost 3,500 Australians had MD with an associated financial impact of \$435 million. Of this, \$236.2 million was lost in productivity and \$117.8 million in cost to carers, as well as many other additional financial burdens experienced by sufferers and their families. With the knowledge that CMT disease is far more prevalent than MD it is possible the costs are similar or more pronounced.

The member for Throsby informs me that my region, Newcastle, has an above average prevalence of this disease. I was not able to establish that but it is part of the problem—we just do not have the data. I would like to know. Research conducted at the University of Newcastle by Dr Fiona Hawke in 2011 has revealed a previously unrecognised link between calf cramps and hand tremors in children with CMT disease type 1, that worsen with age. Of course, we do require greater research into CMT and its causes and increased funding towards such endeavours is essential. I am very pleased to support this motion and thank the member for Throsby for bringing this to our attention.

Ref: <http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;db=CHAMBER;id=chamber%2Fhansardr%2Fc94905e2-4370-462f-b408-d06e0d0a5c8e%2F0388;query=Id%3A%22chamber%2Fhansardr%2Fc94905e2-4370-462f-b408-d06e0d0a5c8e%2F0000%22>

IT'S ON AGAIN!

CMT YOUTH WEEKEND 2013

The Charcot Marie Tooth Association of Australia will be hosting another fun packed weekend in a supportive and caring environment. Don't miss this opportunity to share and connect with other youth with CMT. The pictures tell the story from last year.



WHEN: Friday 6th to Sunday 8th September 2013.

WHERE: Berry Sport & Recreation Centre NSW (just two hours south of Sydney).

AGE: 10 to 17 years with 18+ welcome to be mentors.

COST: \$210 including all meals from Friday dinner to Sunday lunch, passive and adventurous activities and accommodation.

REGISTRATION: For more information regarding registration, sponsorship for Youth Weekend Fund and donations please contact: Jillian via email cmtaussiekids@gmail.com or call mobile: 0428 221 264

CMTAA Inc. www.cmt.org.au

LOTS OF FUN!

SYDNEY SEMINAR 2013

12-13 October 2013

Concord Medical Education Centre



NEW VENUE

NEW FORMAT

NEW WORKSHOPS

NEW NETWORKS

This years Sydney Seminar is taking on a new look, with more opportunities to talk with people just like you. We will still have the seminar on the Sunday but this year we are trying something new. Saturday afternoon we plan an informal get together and short AGM of the CMTAA. This will give everyone time to talk to each other and swap ideas in a relaxed environment.

After the AGM, light refreshments will be served. More talk and hopefully more ideas and input from those attending and a chance for some to meet your state coordinators and become more involved in the State Support Groups if appropriate.

This change is in response to last years seminar feedback forms commenting that there is not enough time to get to know one another during the one day seminar, and the committee wanted to provide such an opportunity in an informal, friendly setting.

The seminar on the Sunday will still have, as expected, world class presentations from medical, allied health and other professionals, but the afternoon will introduce a new concept. The committee are still fine tuning the plans but there will be a number of 'break-out' sessions for seminar participants to elect to attend based on their needs.

The images above show the new venue for our seminar and AGM. It is still in the Concord Hospital grounds but has only recently opened, and provides state of the art sound and audio-visual services, making the seminar experience that much more enjoyable.

Further details will appear in the next newsletter. Put the date in your diary!

TWITTERING THOUGHTS

Reprinted with kind permission of Lenka @lenkaland on Twitter

If I am a house, I have a hundred rooms. Each room is wired for lovely lighting. And with the light, the room works. Everything inside the room is useful and bright. Ready for action.

My house is tidy. My house is strong.

Except. My wiring is muddled. The wires that bring light are fragile. They get mixed signals so they weaken. Rooms get dim. Everything in that room gets covered in cobwebs. But the room is still there, and, with effort, can be useful.

Those rooms are not the problem. Not really.

The problem rooms have no light at all. The wires are cold and quiet. No light shines. Blackness fills these rooms. And cobwebs choke the corners. Everything in those rooms crumbles.

I cannot use lanterns to reach these rooms. The doors are locked and barred. Dark seeps through the cracks, pulling at hallways. These rooms are gone.

And I need them.

I hear a lot, "Oh, weakness? You should exercise."

But the problem isn't the lights. It's the wires connecting the lights. If communication gets cut-off, all the exercise in the world will not touch that light. I can work on this house every hour of the day and it won't matter.

Because my house is haunted. Doors slam shut. Lights flicker on and off. I think I know this house, but the house changes. Every day. Over many days.

Still. I make the most of my time here. Though it's haunted, and broken, and tired, it's my house.

And love shines even with damaged wiring :)

<http://lenkaland.com/my-house>

The author lives in the USA and has Charcot Marie Tooth.



WHAT REALLY HAPPENS

One of our office volunteers Carmen Butcher recently researched the types of enquiries we receive at the National CMTAA office in Sydney. We thought you might find this interesting, and see how diverse a support we provide to our members. These boxes cover a number of months in 2011.

Can CMTAA offer an online forum like in USA ?
Person newly diagnosed with CMT requested an information pack
Contact details for specialist Doctor in Perth
Information pack sent to a CMT patient in Tasmania

Patient with CMT lives in Townsville and requires surgery. Requested surgeon information
Assistance with research project on CMT
Newly diagnosed CMT patient rang for advice. He came into the office for a chat.
Exercises enquiry
CMT knowledgeable physiotherapist information requested
Parent requested an information pack for her son

Person with CMT concerned about his sudden deterioration. Seeking advice
A person with CMT living in New Zealand emailed to say they were struggling to cope with the effects of CMT and they have no one to discuss it with
A personal trainer with CMT requested information and newsletter
Person from Qld rang asking how they go about getting an official diagnosis

Recently diagnosed adult with CMT from Western Australia. Was very upset as her local physio did not believe CMT exists and was giving her children's teachers the wrong information. She did not know who to ask for assistance and support
Financial assistance or grants available to people with CMT
Information pack for a parent with a son with CMT
Information on orthopaedic surgeons with specific knowledge of CMT
CMT clinics for pensioners
4 other requests for information packs

Information requested from a student doing a thesis on CMT
2 people with CMT requested information packs
Contact details for podiatrist with specific CMT knowledge
A family requested information to give to teachers at school

Medication list
Information on CMT and the effects of a particular drug
Parent requested assistance and information for a child struggling at school with CMT
Contact details for Doctor specialising in CMT
2 requests for information packs

Information about any CMT seminars being held in Brisbane
Name of a podiatrist with knowledge of CMT in Brisbane
3 information packs. Two of these requested from people in Ulladulla and Townsend.
Contact details of the CMT office in WA
Where a wheelchair can be bought or hired
Contact details for a variety of medical professionals with knowledge of CMT

List of restricted medications
2 people requested contact details for CMT specialists in Sydney
Contact details for physiotherapists in Melbourne with knowledge of CMT
Benefits of joining CMTAA. Child has CMT
2 information packs requested
Wanted to speak to a person with CMT who has had surgery

This is just a small indication of the types of things our National Office deals with every month. Our thanks must go to the volunteers who keep the ball rolling. Perhaps have a think about helping out. Give the office a call on (02) 9767 5105.

AT THE NATIONAL OFFICE?

Here are some of the responses we had to our Presidents 'CMT Family' email just before Christmas.

From Malcolm Shorthouse:

To start my story I used to drive trucks in the UK and Europe delivering computers and on those days they were a lot heavier and had back problems from this, so the way I walked I put down to this...Then in 1994 I was living in Southport Queensland working for BP and had to stand (for) long hours 8-9 hours a day, so went to see my GP and he said that I had bad muscle wasting of the legs and sent me to a Neurologist and was told I had CMT.

I had tests but they could not tell me what type I had; I also had a test in the UK and that was the same, could not tell what type I had.

It took me some time to come to terms with this then I just said to myself that as there was not a lot I could do about it. I must get on with my life....I now get on with things and try not to dwell on CMT, there are a lot of things that CMT affects. You find this out yourself as you go about life...I think as my Mum would say you just have to get on with it!

From Tim Hansen:

Here's a bit about my past. NSW Police Force 13 years, including 3 years in the Mounted section. And I have X Rays to prove it. Royal Australian Naval Reserve for about 25 years including full time service mainly a musician but other duties too.

Farmer since 2000 with 160 acres. Motorbike rider since the age of 12 years, road and trail. Owner and operator of Hartley Valley Garage Doors for the last 4 years.

From Meryl Grew:

I have type 1A CMT living in a regional area, there is not a wealth of professional knowledge, especially neurological input. However I have a great physiotherapist and orthopaedic surgeon whose knowledge is excellent. During this year I had major reconstructive surgery to both my feet...After 2 episodes of 8 weeks in hospital I have straight feet, have dispensed with my ankle-foot orthosis and have been saved from a wheelchair.

I was amazed at how many allied professional staff had not heard of CMT. I gave them a brochure!

From Joan Izard:

I am ...77 years of age, and had been referred to a neurologist some 24 years ago for severe migraines/ cluster headaches, so when he told me I had CMT I refused to believe it. I was not aware of anybody in my family who had a condition I had never heard of. Some years passed before I was forced to accept it, after confirmation by electrical conduction studies.

I, and my immediate related CMT family have (and are) lucky to have been living happy and active lives, and the fact that I have been incapacitated in the last couple of years is due not to CMT but rather osteoporosis as a result of undiagnosed Coeliac Disease.

And a final word from Kay Hamer:

We can always find someone worse off than ourselves!

NEW 2012 SEMINAR DVD

We would like to make you aware of the availability of our professionally produced recording of the September 2012 Awareness Day Seminar held at Concord Hospital, Concord. Your CMTAA greatly appreciates the time given by Brent Houghton, a professional camera man and member of our CMTAA who has a son with CMT. Brent produced a quality set of 2 DVDs that cover the entire day's program in two parts. The presenters are leading medical and allied professionals with extensive expertise in the research, diagnosis, treatment and management of Charcot-Marie-Tooth Disease. You will also be entertained and encouraged by the interviews with members of our "CMT family".

Speakers Include:

- Professor Garth Nicholson speaking on CMT Research Achievements and Future Research
- Associate Professor Joshua Burns speaking on developments in the management of CMT with an emphasis upon the management of CMT in children.
- Ass/Professor Alison Shield whose specific interests are in CMT biology, pharmacology and toxicology.
- Dr. Helga Hemberger, a clinical psychologist in neuropsychological
- Dr. Che Fornusek speaking on the benefits of exercise for CMT People.
- Dr. Kristy Rose research Physiotherapist in peripheral neuropathy and other therapies.
- Mr. Peter Richards – an interview on how to cope with CMT.

Given the quality and informative content of the DVD's and the increased cost involved in producing the set of 2, the price of \$25 (including postage) is very reasonable. Hoping you will take advantage of the opportunity to view this very informative Seminar in the comfort of your own home.

GRACE WARREN'S HAND EXERCISES DVD

This fascinating, informative DVD is available from our CMTAA National Office for \$15.00. We have lots of information available to us about foot exercises, but not so much about hand exercises. This DVD was recorded with Dr Grace Warren world renowned Educator, Missionary and Surgeon in 2006 and outlines how to help keep your hands moving and pain free.

To order both of these videos, just fill in the form at the back of this newsletter or order through the Membership Application form that can be downloaded from our website: <http://www.cmt.org.au>

A MESSAGE FROM OUR SECRETARY

Dear Members,

For some time, our Association has been aware of the necessity of having local CMT Support Groups for our members and their families. Meetings or 'coffee mornings' could be organized by these Support Groups where ideas can be shared and members could discuss their problems and support each other; just having someone to talk to who has the same or similar problems as yourself could help you and your family in many ways.

CMTAA wants to address this situation by encouraging members of our CMT "Family" to participate in a support group.

If you are interested in joining, please contact the National Office. Your name and phone contact number only will be made available to other CMT members also residing in your area who are also willing to participate.

If you are interested in being the contact person for your group, please let us know.

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 November 2012—31st March 2013

\$500 AND OVER

Mr Richard Kuras	Mr John Speight	Mrs Hilda Newstead
Second Chance Opportunity Store, GyMEA		Lambton High School-Year 12 Students

\$200 - \$499

Mrs Rachell Killen	Mrs Thea Ferguson
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\$100 - \$199

Mrs Barbara Higgins	Mr Roger Macrury	Mrs Joan Izard
Mr Max Baker	Mr John Doyle	Mr & Mrs David Critchley
Mr Adam Glascock	Mr David Cavenagh	Mrs Antonia Karydis
Mr Ken Nicholson	Mrs Kaye Millar	Mrs Beth Shields
Ms Aileen Hooper		

\$50 - \$99

Mrs Janette Llewellyn	Mrs Dian Chick	Mr Robert Hinds
Mrs Carmen Frendo	Dr Susan Dickinson	Ms Marilyn Sciberras
Jon Douglas	Mr Kenneth Dugan	Ms Anne Leggett
Mrs Gaile Fornusek	Mr Lester Rendell	Mrs Elizabeth McKinlay
Mr Dennis Simpson	Ms LS Hoffmann	Mrs Julie Thomas
Mrs Florence Stowell	Mrs Denise Eastwood	Mr Brent Gray
		Mrs Joy Gath

\$20 - \$49

Miss Margaret Lampe	Margaret Adams	Mr Cosimo Camporeale
Mrs Beverley Jurd	Mr Harry Engeland	Mr Richard Seymour
Ms Sarah Jane Mann	Ms Tracey Lee	Mrs Gaile Fornusek
Jill Woodburne	Mrs Maureen Payne	Mr Christopher Sewell
Mrs Marilyn Rowlands	Mrs Kitty Farrow	Mrs Julie Rowe

\$1 - \$19

Mrs Patricia Ingham	Ms Michelle Ehrich	Mrs Dixie Papast
Mrs Margaret Gourley	Mrs Stella Phelan	Mr Patrick Thomas
Mr Mark Kunach	Mr Richard Dillon	Ms Christine Kiem
Mr Brad Miller	Ms Elizabeth Cox	Mrs Janet Robinson
Ms Jane-Anne Sherington	Mrs Jill Ryman	Mr Bruce Nolan
Dr Che Fornusek	Ms Bessie Tselos	

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)

Executive Members

President:	Darryl Beitsch (NSW)
Vice President:	Janeene Payne (VIC)
Treasurer:	Robert Twin (ACT)
Secretary:	Anycie Berkmann (NSW)

Ordinary Committee Members

Editor:	Jillian Critchley (NSW)
Legal Advisor:	Antonia Karydis (SA)
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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Email: neilandjeanpurvis@gmail.com

QUEENSLAND

Brisbane: vacant PLEASE CONTACT CMTAA IF YOU WOULD CONSIDER TAKING THIS ON

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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.

Deadline for next newsletter: 15th July 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:** _____

☐ **NEW MEMBERSHIP**
(\$33.00 per year) \$ _____

☐ **RENEW MEMBERSHIP**
(\$33.00 per year) \$ _____

DONATION TO RESEARCH \$ _____

DONATION TO NAT.ADMIN. \$ _____

DONATION OTHER \$ _____

Donations \$2.00 and over are Tax Deductible.

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

Year of Seminar _____

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

TOTAL \$ _____

Please make cheques payable to :

Charcot-Marie-Tooth Association of Australia Inc.

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***CMTAA
Building 22, Concord Hospital,
Concord NSW 2139***

If undelivered please return to sender at:
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