

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 79 Autumn 2015



CMTAA

Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy



CMT in Australia – A Survey of Cost-Utility, Wellbeing and Management

By Darryl Beitsch

It is with great excitement and anticipation that CMTAA announces the long awaited survey is ready for distribution. This is the first project of its kind in Australia and Dr Scott Denton has produced a survey that is spot on. The survey will be distributed to all members early in April.

Participation is for people 18 years and older who have CMT and is entirely voluntary requiring an investment of 25 to 30 minutes of your time to complete. The survey is not restricted to CMTAA members. If you know of a person with CMT who would like to participate please ask them to contact our National Office (contact details page 10).

Additionally, Dr. Denton will be holding “Focus Groups” throughout Australia for parents, carers, guardians, and spouses of people with CMT. To register your interest in a Focus Group, please contact our National Office through our website www.cmt.org.au or 02 9767 5105 or contact Dr. Denton on: 02 9036 7440 or 0407 294128.



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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



Welcome to our Autumn newsletter. In all my experience as your President, 2015 is shaping up to be one of the most action packed thrillers in the history of your CMTAA. Although we have a long way to go, CMT awareness throughout Australia is gaining momentum thanks to our regional co-ordinators, our CMTAA members and Medical and Allied Health professionals “spreading the CMT word”. There are more regional meetings taking place and I am greatly encouraged by the enthusiasm of our growing number of regional co-ordinators. Our CMT Aussie Kids Weekend is now well established and very popular, the Sydney Awareness Day Seminar attendees are growing, our new website is delivering a significantly improved level of support and our Facebook family is growing. This is the reality of your CMTAA in 2015.

Your Growing CMTAA

The CMTAA is about meeting the needs of those who have CMT as well as others in their family who support them. A significant benefit for our financial members is our new website. We are now delivering an improved level of support than we did with our old site. Specifically this includes the provision of access to the Sydney Awareness Day Seminar videos at no additional charge. Prior to this capability we would charge \$25.00 for these in the form of a DVD. This is excellent value for your annual membership subscription. Additionally, our membership has significantly increased through the simple online membership application process through our website. We are growing and growth necessitates additional resources.

Additional Support

Your Committee has for some time been discussing the need for additional office resources to reduce the load on those currently managing all office activities. Numerous calls have been made to the membership for volunteers to assist; however no one has come forward. It is evident that the President and Secretary should no longer be expected to continue carrying the full office load. The time has now come for the CMTAA to employ someone to undertake defined office tasks. It is now 4 years since we increased our membership subscription rate to \$33.00. It is prudent for any organisation to include regular adjustments to its subscription rates to cover increasing costs. In this context, your CMTAA has adopted the policy that a membership can cover a family at the one address. This would be defined as a ‘household’, as the occupants of a household will all be at the one address but may not be a family. Out of necessity the CMTAA Committee has approved an increase in membership fees for the 2015/16 financial year to \$40.00 per household. A household being all those living at the one address.

2015 Sydney Awareness Day Seminar

Saturday afternoon September 12 and Sunday September 13 at Concord Hospital. More details to follow. Take care, keep moving and keep warm in the cooler months ahead.

Darryl Beitsch

President

NEWS FROM THE REGIONS AND STATES

SOUTH AUSTRALIA

A warm hello from, Antonia, Francesca and Lisa, were buzzing in SA! Our Xmas BBQ at Freemont Park in December 2014 proved to be a great afternoon. We were fortunate to have had the opportunity to share CMT issues with Dr Scott Denton, the author of the CMT survey and partner, Jill who's visit coincided with our event.

In 2015, we continue to hold get-togethers and are excited at the growth of our CMTAA membership made up of 17 CMTAA and 9 SA Regional Facebook followers also boasting over 100 likes.

In March, Antonia attended the quarterly Muscular Dystrophy SA support group for CMT clients, where a representative spoke about TADS Technical Aid to the disabled (SA) Inc.

Focus group meetings with Dr Scott Denton, over the weekend of 24 – 26 April will be, hosted in SA. Letters requesting expressions of interest in attending these sessions, have been sent to members and posted on all Facebook pages and the CMTAA website.

So far, SA CMT coordinators have been heartened by a positive response to the proposed SA CMT Awareness Day 20 September 2015. It has generated interest from attendees, health professionals and presenters. For this proposed event and other future activities SA CMT coordinators are looking to hear from our SA audience and so have put together a short questionnaire, to be circulated late April. We anticipate that this questionnaire will provide both our audience and us with valuable information to help us plan future activities. We encourage and look forward to hearing from as many members and followers. Also planned is a Bunnings BBQ fundraiser and football merchandise auction in the later half of 2015.

We would also like to advise that Francesca left for Germany in February to pursue further studies. She will be sadly, missed and we take this opportunity to sincerely thank her for her many contributions and support to the SA CMT coordinators team. On this note we extend a warm invitation to all our members to come on board the SA CMT coordinators team, your help and input big or small will very much be appreciated.

We invite all SA CMT community members and their friends to join us at our regular gatherings. Our next event planned is on 16 May 2015, where we are taking our support group meetings on the road to the Murraylands of SA at Murray Bridge. The SA team proposes to come to a neighborhood near you!

CMT Team SA remind you to keep your details updated so we can do our best to keep you informed of SA activities. All of our planned events will be posted on the SA regional Facebook page, the CMTAA website and CMTAA Facebook or you can contact one of the coordinators direct.

Finally, CMT Team SA would also like to give a big thank you to head office, for their tireless efforts, that go on in the background to help and support the CMT community. Warm regards Lisa and Antonia

CENTRAL TABLELANDS, NSW

March 1st was a very special day in Bathurst as CMTers got together for the first Central Tablelands support group gathering. It was decided to meet at a café and chat over coffee. The conversation created by eleven people with common interests was rich and varied as were the symptoms and impact of CMT. Overall, the opportunity to meet with others gave a genuine sense of belonging and went some way in reducing the isolation the CMT brings to country residents. It was decided that we will meet again on 18th October at the Café in Hartley at 2pm. Anyone who wants to join us is most welcome.
Sue Hardy – Support Group coordinator

NEWS FROM THE REGIONS AND STATES

GOLD COAST

Hi All, Judy here with greetings from the Gold Coast. I hope you are all fit and well. and keeping cool. Due to health issues, I was unable to attend our last meeting, and I have had some good feedback, and hopefully I will be at the next meet after Easter ! Something that I personally found interesting, is that I live in a complex of six units, and a little while ago two brothers moved into the unit next door, and it turns out that they both have C.M.T, and a couple of weeks ago, a new lady from Homecare came to do my floors for me, and it turns out that her husband is badly affected by C.M.T. I think the point I am trying to make is that more people are becoming aware of it, and it is being spoken about more openly and more often, which can mean that the word is slowly getting out there, thanks to our wonderful C.M.T family. so until next time, take care, and keep smiling!

Judy

TASMANIA

Things have been very quiet in Tassie as most folk are on holidays or away. We had our usual week camping at Coles Bay on the East Coast where it rained every day!! However it really didn't spoil our holiday as it was a good opportunity to "chill out" and just relax with good books and beautiful scenery made better by the soaring sea eagle - what a magnificent sight. These genetic conditions like CMT still present problems as our granddaughter (yet again) returns to Royal Children's Hospital in Melbourne for more genetic testing. She is a puzzle to all the Doctors with a rare condition called Kabuki Syndrome but it now seems that she has another additional syndrome which they are trying to identify. We think she also has CMT but until I have my CMT identified they are not sure what type to test her for. She is a real battler who turned 14 on the 1st March and we've lost count of the number of trips to Melbourne and the surgeries she has undergone which makes my CMT seem insignificant in the scheme of things. Neurologists are still very "thin on the ground" in Tasmania - we need more of them! Congratulations to Darryl and all the staff at Concord for the great work they are doing in making the public more aware of CMT with the very informative website. May 2015 be a good year!

Kind regards Marilyn Kremmer, Tasmanian Co-ordinator.

WESTERN AUSTRALIA

Hello to all in WA and of course, Australia-wide. The WA Committee is working on its first meeting for 2015 but unfortunately, the plans for our meeting in March have not come together so we're currently still working to confirm a date for the next meeting. We will of course keep all of our group informed and let them know once our plans are finalised.

It is sometimes hard to get the presenters we want when we want them - and also in finding subjects that will be of interest to our members. We know we've asked many times before, but please let us know if there's a person or subject that you think will be of interest to the group and we'll endeavour to invite or discuss the item at one of our meetings.

We do like new members to try and come to at least one meeting - to touch base with other people as so much information is exchanged between ourselves - and then they know who we are and what we're aiming to bring to the meetings.

We'd also like to remind people to let us know when they change their contact details - as we have quite a few email addresses that are now out of date - and as we often don't have any other details by which to contact people, they fall off our radar!! Once again - information about our next meeting will be confirmed very soon!!!

Regards, WA CMT Committee

A Farewell to Stella Weir

It is with great sadness that we have to notify our members that a dear friend and staunch CMTAA supporter, past Vice-President, Committee member and national office volunteer passed away in January.

Stella Weir and her husband, Ron were long term members of CMTAA. In early 2003, at a National Committee meeting, Stella volunteered to come in every Wednesday to assist in the National Office at Concord Hospital, Concord. She continued to do this to almost her 80th birthday traveling the long distance from her home and back each week. She had a great sense of humour and was an exemplary volunteer serving our CMTAA, expertly assisting in the office handling all the receipting in our extensive data base and dealing with general office work and enquiries.

When the Association had no President in 2005, Stella took on the position of Acting President as well as that of Vice President managing both roles up until the 2007 AGM when Darryl Beitsch took on the role of President and she remained as Vice President, a position she held up until her retirement in late 2010. Even after her retirement, she continued to attend our Annual Seminars at Concord Hospital.

Stella was an inspiration to all the team at the National Office and tirelessly worked to promote awareness of CMT in the wider community. Our deepest condolences are extended to her husband, Ron and her family and extended family.

Anycie Berkmann, Secretary CMTAA

January 2015 we hear that another of our CMT family has passed on to be in the house of her Lord. Stella Weir was a lovely lady who had great beliefs.

I have known Stella since the early 2000's when she came to our Seminars. Around 2003 she volunteered to help in the National Office. Although we worked on different days sometimes due to circumstances we came together. I found Stella was a willing, tireless worker on behalf of our CMT members and committee.

Stella was enthusiastic about her life and wouldn't let the fact that she had CMT stop her from enjoying life to the full, with her husband Ron beside her with help and encouragement.

She was very surprised and happy at our last seminar to receive a framed certificate of appreciation of behalf of the CMT Association, which she didn't expect. We don't volunteer to get rewards.

Like me, Stella felt she was helping people with CMT to keep going and not give up no matter how trying it can be.

Volunteering in the office can be very rewarding. Stella, Margaret (Dawes) and I became good friends with each other and many of our members.

I close this by saying thanks to you Stella for all you did on behalf of people with CMT.

To Ron, thank you for being an understanding partner which means a great deal to us that have this problem. I know you and your family will miss Stella as I miss my husband and know how you feel.

Phyllis Critchley, Former CMTAA Office Volunteer



A LETTER FROM A CMT AUSSIE KID

Dear Jillian and Peter,

Thank you for all the time and effort you put into CMT Aussie Kids. Before I received the EIO letter when I was participating in the F. A. S. T. trail run at the Children's Hospital at Westmead, I didn't know anyone my age with CMT, I never felt like I fit in and I knew I didn't belong anywhere.

Probably 3-4 months into my personal part of the trial Amy (*Dr Amy Sman—Ed.*) went to get a flyer and handed it to me. It was for the 2014 CMT Aussie Kids Weekend. I wanted to go straight away but after talking with my parents I couldn't 'because I don't know anyone'. I was heart broken. I finally had a chance to meet other people with CMT and I couldn't go. I emailed Jillian when sent me some more information, still couldn't go so I joined the CMT Aussie Kids group.

I can recall sending a message to Jillian on the 1st of June the deadline for the deposit asking if it was too late. Later that night Jillian rang and spoke to my dad for an hour. He got off the phone teary saying how 'That lady seems really nice'. After that call I could go, I was ecstatic.

From that day on the nerves started building but also my countdown had begun.

On the 26th of August it had filially dawned on me that camp was just around the corner, but I spent the night packing for a school trip that was to return on the 28th. I returned home at 9:30 after coming 9th in the State for Science and Engineering, unpacked my stuff from the trip and went straight to bed I had nothing ready for the next day.

It was 7:30 and I had my blankets ripped off. I had an hour to pack, get dressed and make sure I had everything (which I didn't). By 8:30 we loaded the car and we're off. I was too excited to sleep. When we had reached the mountain, dad asked me if I was nervous when I answered no he replies with 'I would be' that make me feel great knowing my dad would be nervous and he gets along with everyone and the nerves got worse.

We had arrived in Berry between 11:30-12 and had to find something to do for 5 PAINFULLY LONG HOURS.....

4 o'clock came around and we headed to the Sport and Recreation Centre, arrived there by 4:30 and waited what seemed like an eternity. A man approached the car, he was later known as Berry Matt. He told us one of the leaders was there already so we got my stuff and headed over where we were talking to Tim and Ewin. Dad was having a great conversation with Tim and because I was of Newbie status dad told Ewin he should look after me.....

When the bus pulled up the nerves vanished, I said good bye to my parents and brother and the best weekend of my life had begun. We made our way into the dorms where I shared a room with Matilda, Eliza and Llana. From there everyone headed out to the basket ball court area where we played and got to know each other, I spent that time talking to Brittany and Francesca. At dinner I sat between Matilda and Zeb, and after that first meal the first time we all sat down together I knew I was sitting with some amazing people and even better friends.

I have made some incredible friends though CMT and although it is more trouble then good I wouldn't change the fact I have CMT if I could. Camp has made me realise although CMT makes you feel alone at times, there are others that feel the same way. I have 'come out of my shell' so to speak and I have started doing my own CMT research online so I can educate those around me.

Without all the effort you put into the organisation of camp every year I would not be the person I am today. Thank you for the countless hours and the huge amount of effort you put in so is 'kids' can enjoy ourselves. I hope to be able to help out in future years even though I still have the 'newbie' status.

Thanks again hope to see you again this year. Steph



2014 Sydney Awareness Day DVD

**The Awareness DVD is now available for postal orders
from the National Office.**

Cost: \$25 including postage and handling.



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

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.

CMT AUSSIE KIDS WEEKEND 2015

Are you a young school kid with Charcot Marie Tooth Disease and feel like a fun, challenging time away from home?

Experience heaps of fun activities like archery, giant swing, cable glide, canoeing, rock climbing and more!

Join us at the NSW Sport & Rec Centre at Berry on the NSW South Coast from

**FRIDAY, 28 AUGUST –
SUNDAY, 30 AUGUST 2015**



To be eligible to attend you only have to be a student at school aged from about 10 years; be a member of the CMTAA (if you're not already a member, contact us) and have some form of CMT, oh... and want to have fun with other kids just like you!



Interested?

Email Jillian at cmtaussiekids@gmail.com or call mobile 0428 221 264 for more details or to register your interest and we'll send you the details

Support CMT Aussie Kids

IF YOU DON'T HAVE KIDS WHO COULD COME TO THIS GREAT WEEKEND, WHY NOT CONSIDER SPONSORING THE WEEKEND BY MAKING A ONE OFF DONATION TO THE CMTAA YOUTH WEEKEND FUND?

YOUR DONATION WILL HELP KIDS WITH CMT LEARN TO DEAL WITH AND MANAGE THEIR DAY TO DAY PROBLEMS AND LOOK TO A BRIGHTER FUTURE.

Check out the videos from previous camps at www.cmt.org.au or on YouTube

TO DONATE TO CMTAA YOUTH WEEKEND or TO FIND OUT MORE, CONTACT CMTAA ON (02) 97675105

THE VERY LONG WALK

Last year 3 friends and I decided to set ourselves a challenge. We registered for the Coastrek – a 55km walk along the Sydney coastline from Codgee to Balmoral. That is an awful long way! Team Red and White was born. Not only were we walking that far but it had to be completed in 18 hours – our team decided we could do it in 12. We all had our barriers to overcome and training schedules to adhere too. Of course, one of my barriers was CMT.

I was diagnosed in my late 20's with CMT. It came as a big surprise and was actually an accidental diagnosis after an injury. No other members of my family were found to have it – lucky me. I was a mutant but not in the cool X-men type of way. I was the clumsy kid and enjoyed travelling and my sedentary lifestyle through my young adulthood. I knew no-one else with CMT, I didn't look any further into prevention or treatments for myself. I lived in a CMT bubble. My son was diagnosed with CMT in 2008, it was the 2 of us in our CMT discovery together. Imagine my surprise then when I discovered a whole CMT family living literally over my back fence. I think I have since asked every CMT related question about everything really. (Thanks Jillian)



I gave up my sedentary lifestyle a few years back as I approach my 40's – I realised it was time to Move it or Loose it. Build up muscle strength and fitness was how I felt I could deal with my CMT and be a role model for my children.

So..... that is how I found myself on the road to a 55km Coastrek. 6 months of fitness training and hours of walking saw my team prepare for the event. I found great allies in my allied health professionals. They were so supportive of my venture and were determined to help me achieve our goal. The biggest reason for people not to finish the event is blisters – 55kms is a long way for anyone to be on their feet. But CMT feet – (well you know as well as me) that's another level all together!

After the initial long training walks I had orthotic adjustments, shoe changes and lost a toenail. I tried strapping techniques and purchased 'the best' socks in the world. I became really fit and ready – until 4 weeks out when lo and behold a foot injury. I was determined though that this walk was going to be done. With modification to my training and management plans established by my allied health supporters, it was another barrier I had to overcome. I was so determined that I was even prepared to wear a boot for months afterwards if need be, which initially was a possibility.

The 6th March 2015 was Coastrek day. An early start to the day, my husband was our support crew, we left home at 5am to pick up the other girls and headed to the start line. We were all a bundle of nerves and excitement. The event was conducted in waves – we were in the 730 am wave. Off we set and charged through the crowd. We were spoilt with the weather and the location. Who could complain about walking around the beautiful Sydney Harbour on a glorious sunny day. Not us!!

Guess what – my feet were fine. No blisters and the painful foot decided part way through the walk to not be painful anymore?? something I have not been able to understand or work out, but one I am happy to accept. CMT did not hold me back or prevent us from completing our challenge. A dodgy tummy and possibly over-hydration slowed us down marginally (but that's another story). Not only did team Red and White finish with smiles on our faces we finished in 11 hours 24 minutes!!

That was 3 weeks ago, I am surprised that I still feel fatigued and tire easily, but so are the rest of my team. So I guess all bodies require time to recover from these endurance events. I am now looking forward to setting myself another challenge – not as long, for the next one. I'm not sure if there was anyone else crossing the finish line with CMT but I felt it was a great achievement for all of us. Suzy Bowdler (she is in the far right of the photo above)

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NEW ZEALAND

Thames and District

Mrs. Gaile Fornusek (See above)

THANK YOU for donations from 1st November 2014—31st March 2015

\$500 and over

Ms. Lynette McMahon

Past Maters and Ladies Assoc. – Masonic Fraternity of Tasmania

\$200 - \$499

Mr. and Mrs. M and K Baker Mr. and Mrs. W. Battaglione

\$100 - \$199

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Mrs. Joan Izard

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Mr. Michael Carroll

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Mr. James Meers

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.

YOU CAN ALSO DONATE ON OUR WEBSITE

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

CMT Aussie Kids Sydney Catch-up 2015

From the 16th of January to the 19th of January, 10 Aussie Kids descended on Sydney for the first ever CMT Aussie Kids Catch-up. All staying in fabulous accommodation that is a Guide camp in Engadine. We were all ready for a fun packed weekend. Friday night was an easy dinner and catching up, whilst trying to watch 'Ted' the movie. Thank you to Ashleigh for driving back home to get the correct cords so we could watch it! Then it was a seemingly early night; that'd be 2am by the teenagers standards.

Saturday saw us heading to the local beach, with some of the Aussie kids catching a bus or train for the first time in their life. A great day at the beach, swimming, eating and catching up, it was a very enjoyable day. Coming home early to go out for dinner that night. 'Old Liberty Diner' in



Engadine was where the teenagers were at, and the big kids (that is parents of some of the CMT kids – Ed) had their catch-up at Little Italy, just around the corner. The night enabled us to see some people we haven't seen in a while and meet some new people. Another massive night watching movies and some more catching up, cause we hadn't seen each other in like 5 months!

Sunday we went to the pool, we weren't at all over swimming because its summer! Then it was time for a big rest, ready for the trip home tomorrow morning, or the big meal we were about to have. Thank you to Kimberly Harvey for donating some money to the catch-up, which allowed us to have a pizza night. 7 pizzas and 13 Macca's Frozen Cokes' later we were all stuffed. -Matilda

I had so much fun seeing some of my best friends again. I loved spending time in Cronulla and just hanging out with some of the most amazing people I know. I can't wait until I see them all again- Steph

Really enjoyed just seeing all the cool people in the group, getting to know everyone just that little bit better- Zeb

I really enjoyed the catchup because I got to see all my favourite people again. One of my favourite activities was the day we spent in Cronulla at the beach and just walking around.- Eliza

I had a really good time seeing everyone again as it had been a while, had a great time, especially in Cronulla.-Eleanor



CMTAA COMMITTEE (2013/2014)

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SEMINAR DVD's & VIDEOTAPES

October 2014

Prof Garth Nicholson—CMT Research and Achievements
Prof Joshua Burns—Developments in the Management of CMT

Dr Andrew Wines—The surgical management of the foot and ankle in CMT patients

Lyndal Douglas—Genetic Counselling

Lois Tonkin—Principles of Pain Management

Judy Gates, Gavin Fernandes, Leanne Huxley—Posture and Balance Workshop

Young CMTers—CMT Aussie Kids Weekend

October 2013

Prof Garth Nicholson—CMT Research Achievements.

Assoc Prof Joshua Burns—Developments in the management of CMT

Dr Alison Shield—General Principles Regarding Medication and CMT

Rebecca Howard, Senior Occupational Therapist, Independent Living Centre—Technology to Improve CMT Quality of Life

Breakout Sessions

Interviews with people with CMT.

A panel of speakers with CMT Q & A

September 2012

CMT Research Achievements—Prof Garth Nicholson
Dev'ts in the Management of CMT—Assoc Prof Joshua Burns

Clinical Psychologist— Helga Hemberger

Physiotherapy in prep for appropriate exercise—Dr Kristy Rose

CMT and Sport—Dr Che Fornusek

Presentation from Inaugural CMT Aussie Kids Weekend

Interviews with the CMT Community

CMTAA research recipient presentation

September 2011

CMT Research Achievements —Prof Garth Nicholson

Dev'ts in the Management of CMT—Assoc Prof Joshua Burns

PGD in IVF— Dr Don Leigh

The role of the Podorthist—Karl—Heinz Schott

Personal Trainers and CMT—Gerry Fenyo

Interviews with the CMT Community

September 2010—Seminar, Sydney

CMT Research Achievements —Professor Garth Nicholson

An International Research Perspective—Dr Joshua Burns

Successful Podiatry for people with CMT—Ms. Anita Hood

Appropriate footwear for CMT sufferers—Mr Casper Ozinga

Success stories from children and adults with CMT

The **CMT CoMmuniTy newsletter** is produced approximately every four months for the information of CMTAA members. The Editor is Jillian Critchley.

All contributions, letters, and enquiries should be directed to the Editor, CMT CoMmuniTy newsletter, 15 Naranga Avenue, Engadine 2233 N.S.W. or email: cmtaa@email.cs.nsw.gov.au

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ARTICLES AND IDEAS

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

Deadline for next newsletter: 15th July 2015

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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