



CMTAA

Charcot-Marie-Tooth Association Australia Inc.

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STRATEGIC PLAN – 2017 to 2020

The Committee of the Charcot-Marie-Tooth Association of Australia (CMTAA) Inc. developed this strategic plan following the 2016 AGM, and it was adopted at the March 2017 Committee meeting. This document represents the ideas and visions of a gathering in October 2016 which included Committee members led by Nelly Sutjipto; representative Regional Coordinators; Researchers; our Past President Darryl Beitsch; our Public Officer; and our office staff member.

This is the first strategic plan produced by CMTAA and represents another important step in the Association's development. Our **goals** have expanded and we now have a **vision** and **mission** to work towards. We have also adopted a **brand name** that clearly identifies our place in the management of **CMT**, a condition which is **recognised globally as the most common inherited neuropathy**.

The Committee encourages all those touched by CMT to read this document and consider how you can contribute to the goals and strategies identified. Together we can progress these over the next 3 years, and through our efforts work towards our vision, 'a World without CMT'.

Brand Name:

CMT Australia

Our Vision:

A World without CMT

Our Mission:

'To unite all those in Australia who are impacted by CMT, the most common inherited neuropathy; empower those with CMT to live their lives to the fullest; and to encourage our community to support CMTAA in its goals.'

Our Community:

Includes:

- *Those of all ages who are affected by CMT;*
- *The families, friends and carers of those with CMT;*
- *Those researching CMT and its impact;*
- *Our Sustaining Partners;*
- *Medical health and allied professionals;*
- *Policy makers;*
- *Relevant advocacy groups; and*
- *Service providers impacting all aspects of CMT management.*

Our Goals:

- 1. To obtain and distribute information related to the welfare of people with CMT.*
- 2. To provide assistance and support to people with CMT, their families, friends and carers.*
- 3. To identify and promote the development of support facilities and services for those impacted by CMT.*
- 4. To increase CMT awareness in the broader community, particularly amongst medical health and allied professions; and the abilities and requirements of people with CMT.*
- 5. To encourage and facilitate research into CMT, and possible cures.*
- 6. To establish alliances with organisations and groups with similar or complementary objectives.*
- 7. To assist in the establishment of similar Associations in our region.*

SWOT analysis:

This analysis is included as an attachment to this plan and represents those Strengths, Weaknesses, Opportunities and Threats that were identified in 2016.

Acknowledgements:

This Strategic Plan was prepared by the 2016/17 CMTAA Committee with the support of the following key stakeholders:

Darryl Beitsch – Past President
Paula Hodgson – VIC Region Coordinator
Peter Critchley – Public Officer
Chris Brown – Member and Office Support

Professor Garth Nicholson
Professor Josh Burns
Dr. Scott Denton

Our Strategies:

Goal 1 - To obtain and distribute information related to the welfare of people with CMT.

- 1.1 Conduct an annual seminar in a capital city and link this to Regional gatherings and web delivery to share the experience.
- 1.2 Encourage sponsorship of seminars and exposure for the sponsor to reduce or eliminate member costs.
- 1.3 Video the annual seminar and release a copy on the CMTAA website.
- 1.4 Build on the success of the 'Coffee and Chat' sessions as a way of connecting members.
- 1.5 Build on the success of the CMTAA Facebook facility to increase exposure and promote positive messages with integrity.
- 1.6 Maintain the newsletter, but trial sending the newsletter as an attachment to those who have requested it be sent by electronic means.
- 1.7 Strategically distribute the booklet 'Moving Forward with CMT' along with an enclosed membership application form.
- 1.8 Maintain and enhance the CMTAA website.

Goal 2 - To provide assistance and support to people with CMT, their families, friends and carers.

- 2.1 This goal requires a well organised and efficiently run organisation which operates at both the national and regional level; has a strategic foundation; and policies and guidelines to support its Committee and volunteers.
- 2.2 Encourage Regions and other special interest groups within CMTAA to seek funding to support their activities and be proactive in their service to their constituents within the context of the national organisation's policies and standards.
- 2.3 Review the CMTAA database to ensure that it includes the information required to support this goal.
- 2.4 Plan and undertake a membership reinforcement campaign through personal contact with members and to gain a better understanding of how CMTAA can assist them.
- 2.5 Consider a program of focus group sessions at a Region level to assess member attitudes to CMTAA.
- 2.6 Establish a communication strategy for Regional Coordinators to assist with member service delivery at a local level. This should include appropriate strategies for each age group.

Goal 3 - To identify and promote the development of support facilities and services for those impacted by CMT.

- 3.1 Investigate the opportunities the NDIS has to offer those with CMT.
- 3.2 Promote the need for an adult multi-disciplinary clinic associated with a major hospital/research organisation.
- 3.3 Approach governments to secure funding for CMTAA to enable it to better service its members and particularly those with CMT.

- 3.4 Investigate the opportunities to work with State based Technical Aid Disability Services to facilitate the development/supply of information and devices to assist those with CMT.
- 3.5 Continue the current CMTAA newsletter, ensuring that this is easily accessible to all members.
- 3.6 Establish a mentoring program as an extension of the Kids Camp to assist those moving from kids to adults.
- 3.7 Continue the Kids Camps but ensure that the activities remain fresh and that there is succession planning for the leadership and support people.
- 3.8 Develop a strategic plan for Youth members.
- 3.9 Plan a return visit for CMT Kids to the UK in 2018 or 2019.
- 3.10 Develop a program to support the parents of youth with CMT.
- 3.11 Develop a program to support the older age group of CMT sufferers.
- 3.12 Review the approach adopted by international CMT groups and see if there are lessons to be learned from these.
- 3.13 Appoint a fundraising person to promote an increase in income to assist all CMTAA goals.

Goal 4 - To increase CMT awareness in the broader community, particularly the medical health and allied professions, and the abilities and requirements of people with CMT.

- 4.1 Stage Regional Seminars as support allows, and invite local medical health and allied professionals and policy makers.
- 4.2 Ensure that seminars are valid Continuing Professional Development events for professionals.
- 4.3 Encourage local financial support for Regional Seminars to reduce (or eliminate) member costs, fund promotion, and facilitate high quality and value for money/time.
- 4.4 Lobby politicians to inform them of the impact of CMT on individuals and to support the Association's goals.
- 4.5 Make use of the material recently produced on behalf of the Association to inform and raise awareness of CMT and the Association.
- 4.6 Appoint a person to oversee a small support team to focus on marketing and raising awareness of CMT and CMTAA.
- 4.7 Prepare a marketing plan for the Association.
- 4.8 Maximise the marketing campaign during September each year to take advantage of this being the International CMT Awareness Month.
- 4.9 Develop a communications strategy for different groups (i.e GPs, Neurologists, allied health professionals, politicians, etc.)
- 4.10 Develop a strategy to provide and promote display posters and CMT information in the clinics of appropriate medical and allied health service providers.
- 4.11 Develop videos to release on the CMTAA website, Facebook and YouTube about the Association and CMT.
- 4.12 Promote the workplace giving options which CMTAA had signed up to.

- 4.13 Target donations at particular programs and demonstrate the benefits of these through promotional videos.

Goal 5 - To encourage and facilitate research into CMT and possible cures.

- 5.1 Develop a communication strategy with researchers.
- 5.2 Work with researchers to determine how CMTAA can best assist them in their research.
- 5.3 Lobby the Department of Health to respond to the recommendations in the report by Dr. Scott Denton.
- 5.4 Maintain the current grant program.
- 5.5 Encourage greater participation in the donation of funds to support the grant program.

Goal 6 - Establish alliances with organisations and groups with similar or complementary objectives.

- 6.1 Meet with representatives of the Muscular Dystrophy Association (MDA) of Australia to assess the potential to establish a Memorandum of Understanding.
- 6.2 Meet with representatives of Carers Australia to determine how the two organisations can collaborate for the benefit of those caring for people with CMT.
- 6.3 Encourage Regions to identify and communicate with local organisations with complementary objectives to explore opportunities for collaboration. These meetings should be face-to-face.
- 6.4 Meet with the Primary Health Network (PHN) to determine how the two organisations can collaborate for the benefit of those caring for people with CMT.
- 6.5 Identify seminars and conferences at which CMTAA could present to build links with other organisations and inform their membership about CMT and CMTAA.
- 6.6 Continue the network with other CMT Associations internationally.
- 6.7 Understand our membership in terms of their demographic and type of their CMT, and their willingness to be involved in trials and focus groups.
- 6.8 Communicate with pharmaceutical companies to inform them of CMTAA and its capacity to assist with trials in Australia.
- 6.9 Expand membership of CMTAA to facilitate participation in trials by being a conduit by which researchers and companies can contact potential participants.
- 6.10 Investigate how to best communicate with the Aged Care Sector to spread the CMT message.

Goal 7 - To assist in the establishment of similar Associations in our region:

- 7.1 Investigate how CMTAA could influence the formation of a similar Association in New Zealand.

SWOT Analysis - 2016

Strengths

1. Experienced management committee
2. The only established CMT specific National support organisation in Australia
3. Solid office procedures and practices
4. Well respected by medical and allied health professionals
5. Enthusiastic office team and management committee
6. Providing quality informative seminars throughout Australia
7. Facilitating support group meetings throughout Australia
8. Facilitating an annual National youth camp that has had a very positive impact on the attendees
9. Recognised for assisting CMT researchers
10. A source of CMT research grants
11. Informative newsletter every 4 months
12. Informative web site
13. A willingness to think outside the square
14. Internationally recognised
15. Providing CMT management advice in response to email, Facebook and telephone enquiries
16. Promoting CMT clinical trials requesting volunteers through our website, Facebook and newsletters
17. Office emails can be accessed remotely
18. A truly National organisation with representation on the management committee from: TAS, ACT, QLD, SA, VIC, and NSW

Weaknesses

1. A lack of succession plans for management committee members
2. Not promoting the need for additional enthusiastic volunteers
3. Due to individual management committee workloads, a lack of strategic planning for the future
4. Not recognised throughout the wider Neurologist community
5. No detailed fundraising plan and a lack of organised large scale fundraising
6. Insufficient research funding streams
7. A need to identify needs and establish specific project task forces to address these needs
8. Not setting annual goals to facilitate growth
9. Security of tenure of our National Office at Concord Hospital
10. Lack of periodic review of office management procedures to keep up with changes

Opportunities

1. Greater co-operation and collaboration with similar international Patient Advocacy Groups
2. Assisting in the setup of a one stop Multi-discipline clinic for people with CMT who are over 18 years of age
3. Promoting the CMTAA as the initial point of contact for case workers dealing with NDIS applications from people with CMT
4. Greater collaboration with other neuromuscular organisations
5. To aggressively promote the CMTAA and CMT awareness to medical and allied health professionals
6. With increased growth, the need for a paid Administrator reporting to the committee
7. With increased growth, the need for an advisory board of CMT researchers and medical and allied health professionals
8. To put into place a 5 year strategic plan for the CMTAA
9. Build upon our recognition in the Federal parliament and NSW parliament (there may be other state or territory parliaments that are aware of the CMTAA)
10. Follow up the Federal Government to act upon recommendations from the report:
"Reducing the Health Burden of Charcot-Marie-Tooth Disease in Australia 2015"

Threats

1. Fragmentation of the CMTAA into individual states and petty infighting
2. A lack of funds to compete with the support offered by other neuromuscular support groups
3. Miss the opportunity of moving with the times and being involved in an advisory capacity for the NDIS
4. Increasing number of un-financial members of the CMTAA
5. A current restricted source of income