

Job description – part time volunteer role

About the organisation

The Charcot Marie Tooth Association Australia Inc. (CMTAA) began as a Support Group in 1988 and was incorporated in 1990 as a registered charity. The public name of 'CMT Australia' was adopted in 2018.

Our objectives are:

1. To obtain and distribute information related to the welfare of people with Charcot-Marie-Tooth disease.
2. **To provide assistance and support to people with Charcot-Marie-Tooth disease, their families, friends, and carers.**
3. To identify and promote the development of support facilities and services for those impacted by Charcot-Marie-Tooth disease.
4. To increase Charcot-Marie-Tooth disease awareness in the broader community, particularly amongst Medical and Allied Health professions; and the abilities and requirements of people with Charcot-Marie-Tooth disease.
5. To encourage and facilitate research into Charcot-Marie-Tooth disease, 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.

About the program

Australia has an excellent health system and patients are offered exceptional treatment, care, support, and opportunities to participate in medical research. However, with so much to offer comes complexity, difficulty in navigating the health system, and challenges knowing about and accessing existing services, which can result in a decreased level of satisfaction with the health system. In addition, with an ever-evolving clinical trial environment and new technologies emerging, we need to create systems that can adapt and keep up to date with these opportunities, while supporting patients and their families. The first point of call for many patients when they are diagnosed with a condition is to go to local patient organisations for information and support. The Pathways Telehealth Service makes the most of this relationship by establishing a central point of contact within non-profit organisations - a specialist, Pathways nurse – to help patients and their families access existing services and connect them with opportunities to participate in medical research and patient feedback initiatives. CMT Australia is one of the partner organisations within the Pathways program.

About the role

The role is part time on a volunteer basis, working from home.

Summary of duties

- Assists all patients through the healthcare system by identifying gaps in care and developing a holistic care plan
- Participates in network meetings and quality improvement initiatives
- Engage in nurse education programs within the network
- Supports patient self-management of disease and nurse-led assessments and interventions
- Manages high-risk patient care, including management of patients with multiple co-morbidities or high risk for readmission to a hospital setting
- Participates in data collection, health outcomes reporting, and programmatic evaluation
- Evaluates clinical care, utilisation of resources, and development of new clinical tools, forms, and procedures
- As part of your role, you will conduct administrative tasks and small projects to support patient populations such as developing information materials, coordinating support groups

Education and experience

- Graduation from an accredited university with a Bachelor of Nursing Degree with AHRPA registration
- Expertise and/or excellent knowledge of or willingness to learn about Charcot-Marie-Tooth disease (CMT), disabilities, NDIS, and the Australian health system
- Proficient computer skills, including Microsoft Office (specifically Word and Excel)
- 5 years minimum experience in a clinical setting
- Self-disciplined, energetic, passionate, innovative
- A team player that can follow a system and protocol to achieve a common goal
- Highly organized and well-developed oral and written communication skills
- Demonstrates sound judgment, decision-making and problem-solving skills
- Able to maintain confidentiality with all aspects of information in accordance with practice and local legislation/regulations

Applications

Please send your CV and short cover note to administration@cc-dr.org by 5pm, Friday 23 March 2024.