



Information for Prospective Trustees

CMTUK

3 Groveley Road
Christchurch
Dorset
BH23 3HB

Charity Number: 1112370

CMTUK (CMT United Kingdom) is a small national facing charity supporting people living with Charcot-Marie-Tooth disease and related conditions across the United Kingdom.

CMT is a group of over 120 identified related conditions that affect the peripheral nerves. Charcot-Marie-Tooth Disease is a genetic condition that damages peripheral nerves. These nerves are responsible for passing on commands from the brain to the muscles (motor nerves) and for passing information to the brain about sensations, such as pain, heat, cold, touch, importantly for balance – where your joints are in space (sensory nerves).

When these are damaged, people are said to have a neuropathy.

Because of this nerve damage, people with CMT may find that some of their muscles become slowly weaker over time, particularly in their feet and hands.

Some find that feeling becomes dull, or numb, in the same areas.

The severity of CMT on individuals varies greatly even within the same family.

The name Charcot Marie Tooth comes from the people who described the condition in 1886: Jean-Martin Charcot, Pierre Marie and Henry Tooth, it is also known as Hereditary Motor and Sensory Neuropathy (HMSN) and Peroneal Muscular Atrophy (PMA).

CMTUK roots date back to 1986 when a small group of patients came together to support each other. This developed over time and registered as a charity and limited company in 2005.

CMTUK is seeking to recruit a number of new trustees to support the organisation going forward and is keen to increase the diversity of the existing board.

CMTUK board consists of up to 10 trustees (currently 5). Trustees live across the UK and meet at least four times a year for board meetings with regular catch-up meetings. The meetings are mostly held virtually with the aim to have at least one in person meeting annually, usually held the evening before the AGM and annual conference (these have tended to be in the West Midlands area). Costs for travel to meetings, meals and accommodation (if required) are met by the charity.

Trustees are elected by the membership at Annual General Meetings and stand for a term of three years. They can stand for a further two terms (a total of 9 years) after which trustees are required to step down for a minimum of 12 months.

The board has sub-committees on which the trustees sit. These meet between board meetings and have an overview of particular areas of the charity's activities.

Currently these are: Finance, Communication, Strategy, Research, CMT Kids.

The charity currently employs four members of staff (all part-time):

Chief Executive – Simon Bull
Information and Support Advisor – Kim Shires
Accounts Manager – Lisa Yeates
Administrator – Chris Smith

There are volunteers in the following roles:

Regional Support Group coordinators
Editor of ComMenT (the CMTUK magazine).

CMTUK offers the following services to its membership:

Helpline (Mon – Fri. 9am to 2pm)
Website (cmt.org.uk)
Information (leaflets)
Regional Support Groups
Conferences and events
Magazine (ComMenT)
Occasional Newsletter
Facebook Groups
Other social media content (YouTube, Twitter, Instagram)

CMTUK promotes its annual awareness month campaign which, in line with other European CMT organisations, is in October and supports the USA awareness month in September.

CMTUK is a founding member of the European CMT Federation (ECMTF), which seeks to bring together the patient groups across Europe and further afield to promote joint working for the benefit of all those living with CMT.

CMTUK is aware of the need to influence government policy and thinking related to CMT and the wider neurology and rare disease communities and does this through its membership of the Genetic Alliance and the Neurological Alliance.