Study title: Survey exploring the use of walking aids in people with Charcot-Marie-Tooth disease

You are being invited to take part in a research study exploring how people with CMT choose to use mobility aids. A mobility aid is a device designed to assist a person to get around when walking is difficult e.g. walking stick, cane, hiking pole (Nordic walking pole), wheeled walker, frame, wheelchair or other.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Purpose of the study
Balance impairments and falls are more common in people who have Charcot Marie Tooth (CMT) than in people without the condition. CMT is a condition affects the nerves, causing a variety of symptoms including altered sensation and muscle weakness. Most often the symptoms are most evident in the feet and hands, but they can progress very slowly moving closer to the trunk.

We know that people with CMT sometimes use aids to help them balance and walk, though we do not know many details about this. This survey aims to explore use of mobility or walking aids or devices by people with CMT.

Why is the research being done?
Although anecdotally we know that people with CMT often use the support of aids or devices to help with their balance and walking, no studies currently exist which tell us what people use, how often and why. This study aims to find this out, along with additional information on activity levels, how you feel about walking aids and your confidence to do certain things.
Knowing this information will enable us to better understand the needs of people with CMT with the aim of influencing the treatment you receive.

**Why have I been chosen?**
You have been asked to consider participating in this study because you have a diagnosis of CMT and a member of CMT United Kingdom. We are interested in the views of people with all types of CMT who both do and do not use mobility aids.

**Do I have to take part?**
No, you do not have to take part. It is up to you to decide whether or not to take part. If you choose not to take part, any future or current participation or relationships with Kingston University and St Georges University of London will be unaffected. If you decide to take part, you will be provided either with a link to a web based survey or given a paper copy to complete with a stamped addressed envelope send to the research team. If you choose not to participate you will not be required to do anything. No further contact will be made with you.

**What is involved in the study?**
*a. What will happen to me if I take part?*
You will be asked to complete a survey that you can access via CMT United Kingdom, either through a web link, a posted paper copy or at the annual general meeting in April 2016. The survey should take no longer than 30 minutes to complete. The survey will be completely anonymous; will we be unable to identify you from the information we ask you. If you complete and submit the survey, we will take this to mean that you consent for us to use the anonymous data you provide in your answers.

*b. How long will I be involved in the study?*
Your participation in the study will last only for the length it takes you to complete the survey. Once this has been completed your involvement in the study would have finished.

**What are known risks in participating?**
There are no anticipated risks in taking part. It is possible that some people may find thinking and recording their experiences upsetting. If this happens, you can stop the survey or take a break at any time. You may also find it beneficial to speak to your GP to discuss whether any additional support may help you.

**What are the possible benefits of taking part?**
There are no direct benefits to you in taking part. However, we hope that the information we get from this study will help to inform future research and may improve the advice and treatment given to patients with CMT in the future.
What will happen to the results of the study?
The study findings will be written up as part of a PhD looking at ways to improve balance in people with CMT. The data will be written up and submitted to academic journals, presented to health professionals at conferences and published by CMT United Kingdom. In all of these cases, you will not be identified in any way.

Who has reviewed this study?
The study has been looked at by an independent group of people called the Faculty Research Ethics Committee to protect your safety, rights, and dignity. They have given a favourable opinion.

What if I have a complaint?
If you wish to complain about any aspect of the research, please contact the study supervisor, Dr. Gita Ramdharry using the details given below.

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Thank you very much for taking the time to consider your involvement in our study. Please keep this copy of the information sheet and do not hesitate to contact us if you have further questions.