Why am I here?
This is a research study. Only people who choose to take part are included in research studies. You are being asked to take part in this study because you are affected by Charcot-Marie-Tooth disease. Please take time to make your decision. Talk to your family about it and be sure to ask questions about anything you don’t understand.

Why are they doing this study?
This study is being done to find out more information about people with Charcot-Marie-Tooth disease. The doctors at Wayne State University are collecting information about people with Charcot-Marie-Tooth disease to store in a database, which is like a list. People who do research on Charcot-Marie-Tooth disease can use this list of information to learn more about Charcot-Marie-Tooth disease.

What will happen to me?
You will be asked to give us information about your health history and your family’s history. You and your parents/guardian will fill out forms with this information. Your doctor will be asked to fill out forms on your health information. Your parents/guardian will be asked to sign a different form to give us your medical records about Charcot-Marie-Tooth disease.

How long will I be in the study?
At first you will fill out several forms. Your information will remain in the study for as long as the database, or list, is maintained. This is an open-ended study, meaning we do not know when the study will end. You will be contacted every year to fill out a short update form.

Will the study help me?
Joining in this study will not help your problems to get better. However, by giving us your information, you will help doctors learn more about Charcot-Marie-Tooth disease, which might help learn better ways to diagnose and treat people with Charcot-Marie-Tooth disease.

Will the study hurt?
This study will not hurt you. If you have any concerns from being in the study you should tell your parents/guardian so that they can call your study doctor right away.

What other options are there?
The only other option is not to participate in this study.

Do my parents know about this?
This study was explained to your parents/guardian and they said that you could be in it. You can talk this over with them before you decide.
What about confidentiality?
Every reasonable effort will be made to keep your medical records confidential. But we do have to let some people look at your study records and maybe your hospital records.

We will keep your records private unless we are required by law to share any information. The study doctor can use the study results as long as you cannot be identified.

What if I have any questions?
For questions about the study please call Dr. Michael Shy or one of his research team members at (313) 577-5273, Monday through Friday 8:00 am – 4:00 pm. If you have questions or concerns about your rights as a research participant, you can call the doctor in charge of research studies at Wayne State University at (313) 577-1628.

Do I have to be in the study?
You don’t have to be in this study if you don’t want to or you can stop being in the study at any time. Please discuss your decision with your parents/guardian and doctor. No one will be angry if you decide to stop being in the study.
AGREEMENT TO BE IN THE STUDY

Your signature below means that you have read the above information about the study and have had a chance to ask questions to help you understand what you will do in this study. Your signature also means that you have been told that you can change your mind later and withdraw if you want to. By signing this assent form you are not giving up any of your legal rights.

____________________________________________  _______________
Signature of Participant (13 yrs & older)                          Date

____________________________________________
Printed name of Participant (13 yrs & older)

____________________________________________  ________________
**Signature of Witness (When applicable)                          Date

____________________________________________
Printed Name of Witness

____________________________________________  ________________
Signature of Person who explained this form                          Date

____________________________________________
Printed Name of Person who explained form

** Use when participant has had consent form read to them (i.e., illiterate, legally blind, translated into foreign language).