# CMT NORTH AMERICAN DATABASE FAMILY HISTORY QUESTIONNAIRE

Date ___________________________________________

How did you hear about the database?

_______Had genetic testing and a packet was sent to the referring physician from Athena Diagnostics

_______CMT Association _______CMT International

_______Wayne State University Website _______MDA Website

_______Other_____________________________________________________

To complete this questionnaire, one person in the family is identified as the **SOURCE PERSON**. This person must have Charcot-Marie-Tooth disease (CMT). All other persons in the family are identified in terms of their relationship to this Source Person, (i.e., all questions will be asked about the Source Person's siblings, parents, etc.). The source person may not be the person who is completing the questionnaire and therefore we ask information about the person who fills out the questionnaire. If other family members are completing a questionnaire there may be more than one Source Person in a family.

Please complete the questionnaire as thoroughly as possible. Do not omit people because they do not show symptoms of CMT. Please do not let the fact that you cannot answer some portions or that some portions do not apply to you, keep you from returning the questionnaire. We are interested in any information you can provide. **For all women that are listed, please use their maiden names.**

**Person completing this family history questionnaire:**

Name_____________________________________________________________
First MI Maiden Last

Address___________________________________________________________
Street City State Zip Code

Daytime #__(__________)____________________________________________
(Area Code)

If you are not the Source Person, what is your relationship to the Source Person?____________________

**SECTION A:** Information about the **SOURCE PERSON** SEX: _______F ______M

Name_____________________________________________________________
First MI Maiden Last

Address___________________________________________________________
Street City State Zip Code

Daytime Phone#__(__________)_______________________________________
Area Code

Date of Birth____________________________________ LIVING: _______Yes _______No
Month Day Year

If deceased, date and cause of death

_________________________________________________________________
Month Day Year Cause of Death

Circle the appropriate answers.

| Ethnicity | Race |
|---|---|
| 1 Hispanic or Latino | 1 American Indian/Alaska native |
| 2 Not Hispanic or Latino | 2 Asian |
| 3 Don't Know | 3 Black or African American |
| | 4 Native Hawaiian or Other Pacific Islander |
| | 5 White |
| | 6 More than one race |
| | 7 Don't know |

Spouse of Source Person

______________________________________________________________________________
First MI Maiden Last

Date of Birth of Spouse______________________________________ LIVING: _____Yes ______No
Month Day Year

If deceased, date and cause of death ______________________________________________________
Month Day Year Cause of Death

**SECTION B**: Information about your **CHILDREN**

Please include miscarriages or stillbirths. If more space is needed, please enter information about your children on Continuation Form 1 at the end of this FHQ. Indicate continuation of **SECTION B.**

| Name | | Sex | Birthdate | | | Living? | Date of Death | | | One parent is you, name the other parent | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Have any of your children been **DIAGNOSED** with CMT? _______Yes _______No
Are any of your children **showing symptoms** of CMT? _______Yes _______No

If you answered yes to either of the previous questions, please complete this table for each child who is affected.

| Name | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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**SECTION C:** Information about your **GRANDCHILDREN**
Please provide information about your grandchildren, completing table for each of your children **<u>who has children</u>**. You do not need to fill out information for your children who do not have children. If more space is needed, enter information about your grandchildren on Continuation Form 1 at the end of this FHQ. Indicate continuation of **SECTION C.**

Name of the your child:_____________________________________________________________

| Name this child's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
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| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these grandchildren have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Grandchild | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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Name of your child:_______________________________________________

| Name of this child's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
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Do any of these grandchildren have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Grandchild | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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Name of your child:_______________________________________________

| Name of this child's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these grandchildren have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Grandchild | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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Name of your child:_______________________________________________________________

| Name this child's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
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| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these grandchildren have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Grandchild | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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Name of your child:_______________________________________________________________

| Name this child's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
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| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these grandchildren have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Grandchild | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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**SECTION D:** Information about your **SIBLINGS** (sisters and brothers)
Please include both full and half-siblings. Full siblings have the same mother and father as you. Half-siblings share one parent. Begin with the oldest full sibling. **Do not include yourself**. If more space is needed, please enter information about full siblings on Continuation Form 1 at the end of the questionnaire. Indicate continuation of **SECTION D**.

| Name of Brother or Sister | | Sex | Date of Birth | | | Living | Date of Death | | | Parent's Names | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Y/N | Da | Mo | Yr | Father | Mother |
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Have any of your siblings been **DIAGNOSED** with CMT? _______Yes _______No
Are any of your siblings **showing symptoms** of CMT? _______Yes _______No

If yes, please complete this table for each one who is affected.

| First Name of Sibling | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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**SECTION E:** Information about your **NIECES AND NEPHEWS** (i.e., children of the brothers and sisters)
Please fill out one set of tables for each brother or sister **who has children.** If more space is needed, please enter information about nieces and nephews on Continuation Form 1 at the end of the questionnaire. Indicate continuation of **SECTION E**.

Name of your brother or sister:____________________________________________________________

| Name of this brother or sister's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **Last** | **First** | **M/F** | **Mo** | **Da** | **Yr** | **Y/N** | **Mo** | **Da** | **Yr** | **Last** | **First** |
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Do any of these nieces or nephews have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Niece or Nephew | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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Name of your brother or sister:_______________________________________________

| Name of this brother or sister's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these nieces or nephews have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Niece or Nephew | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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Name of your brother or sister:_______________________________________________

| Name of this brother or sister's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
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| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these nieces or nephews have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Niece or Nephew | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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Name of your brother or sister:_______________________________________________

| Name of this brother or sister's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these nieces or nephews have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Niece or Nephew | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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Name of your brother or sister:_______________________________________________

| Name of this brother or sister's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these nieces or nephews have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Niece or Nephew | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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**SECTION F**: Information about the **PARENTS** of the Source Person.

Father's Name ______________________________________________________________
(First) (MI) (Last)

Date of Birth ________________________________ Living: _______Yes _______No

If deceased, date and cause of death ____________________________________________

Mother's Name ______________________________________________________________

(First) (MI) (Maiden) (Last)

Date of Birth ______________________________________________ Living: _______Yes _______No

If deceased, date and cause of death ________________________________________________________________

Does (did) either parent **show symptoms** of CMT? _______Yes _____No _______Don't Know
If yes, which one? _______Father _______Mother
If parent had CMT, at what age did the first symptoms appear?_______________________________
Has the disease been diagnosed by a physician? _______Yes _______No _________Don't Know
If deceased, was an autopsy performed? _______Yes _______No _________Don't Know

**SECTION G**: Information about your **GRANDPARENTS**
Please give the following information about your grandparents on the side of the family where CMT appears (i.e., mother's side or father's side). If you do not know whether CMT was on your mother's side or father's side, go to **SECTION J**.

Are these your _______mother's parents (maternal) or _______your father's parents (paternal)

Grandfather's Name ____________________________________________________________________
(First) (MI) (Last)

Date of Birth ________________________________________ Living: _______Yes _______No
(Month) (Day) (Year)

If deceased, date and cause of death ________________________________________________________________

Grandmother's Name ____________________________________________________________________
(First) (MI) (Maiden) (Last)

Date of Birth ________________________________________ Living: _______Yes _______No
(Month) (Day) (Year)

If deceased, date and cause of death ________________________________________________________________

Did either grandparent have CMT? ______Yes _______No _______Don't Know
If yes, which one? _______Grandmother _______Grandfather
At what age did the first symptoms appear?___________________________________
Has the disease been diagnosed by a physician?_______Yes _______No _______Don't Know
If deceased, was an autopsy performed?_ _______Yes _______No _______Don't Know

**SECTION H**: Information about your **AUNTS and UNCLES**
In the table below, please list all of the children of the above two grandparents, i.e., your aunts and uncles. Also list all of the affected grandparent's children by other marriages, indicating the name of the other parent in the table below. If more space is needed, please enter information on Continuation Form 1 at the end of the questionnaire. Indicate continuation of **SECTION H**.

| Name of Aunt or Uncle | | Sex | Birth date | | | Living? | Date of Death | | | One parent is the grandparent, name the other parent | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these aunts or uncles have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Aunt or Uncle | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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**SECTION I:** Please provide information about your **COUSINS** (children of aunts and uncles) by filling in one set of tables for each aunt or uncle **<u>who has children.</u>** If more space is needed, please enter information about cousins on Continuation Form 1 at the end of the questionnaire. Indicate continuation of **SECTION I**.

Name of your aunt or uncle:_______________________________________________________________

| Name this aunt or uncle's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these cousins have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Cousin | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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Name of your aunt or uncle:_______________________________________________________________

| Name of this aunt or uncle's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these cousins have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Cousin | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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Name of your aunt or uncle:_______________________________________________________

| Name this aunt or uncle's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these cousins have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Cousin | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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Name of your aunt or uncle:_______________________________________________________

| Name this aunt or uncle's children | | Sex | Birth date | | | Living? | Date of Death | | | One parent is named above, name the other parent | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Y/N | Mo | Da | Yr | Last | First |
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Do any of these cousins have CMT? _______Yes _______No
If yes, please complete this table for each one who is affected.

| First Name of Cousin | Showing symptoms? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | If Deceased was an autopsy performed? Y/N | Current or Last State of Residence |
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**SECTION J**: Additional Information

Please list any other family members, not already listed, who have been **DIAGNOSED** with, or are **showing symptoms** of CMT and explain their relationship to the Source Person.

| Name | | Sex | Birth date | | | Date of Death | | | Parent's Name | Relationship to Source Person |
|---|---|---|---|---|---|---|---|---|---|---|
| Last | First | M/F | Mo | Da | Yr | Mo | Da | Yr | | |
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**SECTION K: GENETIC TESTING INFORMATION**

Besides yourself, has any affected person in your family been diagnosed with CMT? Yes No Don't Know

If yes, complete the following table for each diagnosed person. Indicate the result of each genetic test as positive (P), negative (N) or inconclusive (I).

| Name | CMT Type (select from list 1 at bottom of this page) | HNPP point mutation (PMP22 gene) | HNPP deletion (PMP22 gene) | CMTX point mutation (Connexin 32 gene) | CMT1A duplication (PMP22 gene) | CMT1A point mutation (PMP22 gene) | CMT1B point mutation (MPZ gene) | CMT1C point mutation (LITAF) | CMT2A (1) point mutation (KIF1B) | CMT1D point mutation (EGR2 gene) | CMT2A (1) point mutation (KIF1B gene) | CMT2A (2) point mutation (MFN2 gene) | CMT2B point mutation (RAB7 gene) | CMT2D point mutation (GARS) | CMT2E point mutation (NF-L gene) | CMT2F point mutation (HSP27/ HSPB1) | CMT4A point mutation (GDAP1 | CMT4B1 point mutation (MTMR2 gene) | CMT4B2 point mutation (SET binding factor 2) | CMT4D point mutation (NDRG1 gene) | CMT4E point mutation (EGR2 gene) | CMT4F (Periaxin) | dHMN II (HSP22 / HSPB8) | dHMN V (GARS) | ALS4 (Senataxin) | HMN Dynactin (DCTN1) | HSN (SPTLC1) | OTHER, describe ______ |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Example: John Doe** | **CMT1** | **N** | | **N** | **P** | | | | | | | | | | | | | | | | | **N** | | | | | | |
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**List 1:** CMT1 CMT1A CMT1B CMT1C CMT1D CMT2 CMT2A (1) CMT2A (2) CMT2B CMT2C CMT2D CMT2E

CMT2F HNPP CMTX CMT4 CMT4A CMT4B1 CMT4B2 CMT4C CMT4D CMT4E CMT4F

dHMN I    dHMN II    dHMN III    dHMN V    dHMN VI    dHMN VII    dHMN Jerash    ALS4    HMN Dynactin    HSN    Other

**CONTINUATION FORM 1**

| Name | Sex M/F | Showing symptoms ? Y/N | Age First Symptoms Appeared | Diagnosed by a Physician? Y/N | Date of Birth | Living? Y/N | Date of Death | If deceased was an autopsy performed? Y/N | Parent/Spouse Name |
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