UNIVERSITY OF IOWA CMT CLINIC
CMT QUESTIONNAIRE FOR AFFECTED INDIVIDUALS

SECTION A: INTRODUCTION

The purpose of this questionnaire is to obtain information about those individuals affected with Charcot-Marie-Tooth disease (CMT) whose families are participating in the CMT research study.

We appreciate your attempts to answer all questions as fully as possible. However, if you do not have all the information necessary to complete a question, don't skip it. Include as much as you know. Because we are studying people with all types of CMT mutations and are also collecting information on people who are deceased, some questions may not apply to you. Also, we appreciate any additional information that you feel would be helpful in studying CMT. Space is provided at the end of the questionnaire. If you are answering for more than one affected person, please use a separate questionnaire for each individual. All information will be kept in the strictest confidence. Please return the questionnaire within three weeks if at all possible. There are some places in the questionnaire that ask for the names and contact information for your physicians. We are requesting this information so that we may obtain medical records relating to your CMT. Please remember to sign and send back the consent form to obtain your medical records when you send back this questionnaire.

DATE:_____

THE PATIENT (THE AFFECTED INDIVIDUAL):

NAME:_____
First Middle Last Maiden

ADDRESS (If Living):_____
Street City State Zip Code

TELEPHONE:_____
Area Code Number

EMAIL ADDRESS:_____

PERSON COMPLETING THE QUESTIONNAIRE:

NAME:_____
First Middle Last Maiden

ADDRESS:_____
Street City State Zip Code

TELEPHONE:_____
Area Code Number

RELATIONSHIP TO PATIENT:_____

SECTION B: INFORMATION ABOUT THE PATIENT

Please answer the questions in this and other sections for the patient, whether living or deceased. If the patient is deceased, all questions should be answered as they pertain to his or her lifetime.

Birthdate:_____ Birthplace:_____ Living: Yes_____ No_____
Mo Day Year City or County State

If deceased, date (or age) of death:_____ Cause of death:_____

Circle the appropriate answers:

Gender	Ethnicity	Race
1 Male	1 Hispanic or Latino	1 American Indian/Alaska native
2 Female	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

Have you ever been employed? Yes_____ No_____ Patient is a child_____ (skip to Section C)

If yes, what is your current or last job? _____

Have you ever been exposed to any toxic substances? Yes_____ No_____

If yes, please specify: _____

Has CMT ever affected your job? Yes_____ No_____

If yes, please check all that apply:

___Unable to perform physical tasks with hands such as writing and/or typing
___Unable to perform physical tasks with legs such as walking, standing, balance, bending, or using stairs
___Disabling fatigue
___Quit job / laid off because of CMT
___Retired early because of CMT
___Unable to manage transportation to and from work
___Other_____

SECTION C: CLINICAL HISTORY

At what age did you begin to walk? 6-12 Months ____ 1-2 years____ over 2 years____ Don't Know____
Did you walk on your tiptoes when learning to walk? Yes_____ No_____ Don't Know_____
Were other developmental milestones (i.e., sitting up, talking, etc.) on time? Yes __No __Don't Know___
If no, please specify_____

At what age did your symptoms begin? _____years _____No symptoms _____Don't know

At what age were you diagnosed with CMT? _____years _____Not diagnosed _____Don't know

First Symptoms Included (check all that apply):

___weakness in hands
___abnormal sensation in hands/arms
___pain in feet/legs
___abnormal sensation in feet/legs
___muscle loss in feet/legs
___hammertoes
___frequent tripping/falling
___difficulty climbing stairs
___don't know
___pain in hands/arms
___carpal tunnel syndrome
___weakness in ankles (spraining ankles frequently)
___foot drop
___high arches
___general clumsiness
___poor balance/loss of balance
___difficulty walking
___other

As a child, were you able to (check all that apply)?

___ride a bicycle
___roller skate/ice skate
___keep up with peers in physical activities
___run
___don't know/ can't remember

If you were previously diagnosed with CMT, what type of CMT was diagnosed? **Choose one response.**

____HNPP ____CMT type 1 ____CMT type 2 ____CMT type 4 ____Unknown

Testing performed to make diagnosis (check all that apply)

____Genetic Testing by a blood test
____Nerve Biopsy
____EMG or Nerve Conduction Velocities
____Muscle Biopsy
____MRI/CT scan
____Other:_____

If you checked genetic testing, please complete the following to the best of your ability:

Year Tested:_____ **Laboratory:_____**

Genes Tested:_____
_____

Test Results: Positive_____ Negative_____ Inconclusive_____

Physician who made the diagnosis of CMT:

SPECIALTY: _____General Practitioner _____Neurologist _____Orthopedic Surgeon
_____Physiatrist (rehab doctor) _____Other:_____

NAME:_____
First Middle Last Maiden

ADDRESS:_____
Street City State Zip Code

TELEPHONE:_____
Area Code Number

Physician who ordered genetic testing:
SPECIALTY: _____General Practitioner _____Neurologist _____Orthopedic Surgeon
_____Physiatrist (rehab doctor) _____Other:_____

NAME:_____
First Middle Last Maiden

ADDRESS:_____
Street City State Zip Code

TELEPHONE:_____
Area Code Number

Physician currently treating the patient's CMT:
SPECIALTY: _____General Practitioner _____Neurologist _____Orthopedic Surgeon
_____Physiatrist (rehab doctor) _____Other:_____

NAME:_____
First Middle Last Maiden

ADDRESS:_____
Street City State Zip Code

TELEPHONE:_____
Area Code Number

Have there been any events in your life which have made your CMT worse? _____Yes _____No
If yes, check all that apply:
___pregnancy ___ accident
___surgery ___fall
___medications ___period of high distress (i.e. death, moving, job loss, etc.)
___other medical illnesses ___employment situation
___other event, please specify:_____

For women who have been pregnant, how many pregnancies have you had?_____
How many miscarriages have you had?_____
Did pregnancy worsen the symptoms of CMT? _____Yes _____No
If yes, was the effect _____Temporary _____Permanent?

SECTION D: CURRENT SYMPTOMS

Do you have muscle weakness? _____Yes _____No _____ Don't Know
Has your condition gotten worse over the last 6 months? _____Yes _____No
Has your condition gotten worse over the last 12 months? _____Yes _____No
Has your condition remained the same for 12 months? _____Yes _____No
Has your condition remained the same for 24 months? _____Yes _____No

Please check all areas where you are weak.

___ Right arm ___Left arm
___ Right leg ___Left leg
___ Right hand ___Left hand
___ Right foot ___Left foot

Are both sides weak? _____ Yes _____No
If yes, which is worse? _____Right _____Left

Check each of the statements that apply:

___ Sometimes I am full of energy
___ I feel tired much of the time
___ I am unable to raise my arms above my head
___ I am unable to unscrew a jar
___ I have difficulty writing
___ I have difficulty tying my shoelaces
___ I have difficulty getting up out of a chair
___ I have difficulty climbing stairs
___ I have difficulty standing on my tiptoes
___ I catch my toes on rugs/curbs
___ I am unable to rise from a kneeling position without the use of my arms

Do you get muscle cramps or "charley horses"? _____Yes _____No _____ Don't Know
If yes, check all that apply

___Cramps are in muscles of both lower and upper limbs
___Cramps are in muscles of the lower limbs only
___Cramps are in muscles of the upper limbs only
___Cramps are primarily after exercise
___Cramps are primarily at night
___Cramps have increased in frequency progressively since their onset
___The cramps are painful

How would you best describe your handwriting?

___Normal
___Slow or sloppy; all words are legible
___Not all words are legible
___Able to grip pen, but unable to write
___Unable to grip pen

Is your handwriting getting worse? _____Yes _____No

Do you have any trouble walking? _____Yes _____No

If yes, please choose the best description below

___Occasional ambulating difficulties
___Frequent ambulating difficulties
___Require assistance occasionally
___Require assistance always
___Cannot walk, but has purposeful leg movements
___Cannot walk at all

At what age did you require the following aids (check where applicable)

	0-10 years	10-20 years	20-30 years	30-40 years	Over 40 years
Shoe inserts					
Orthotic shoe inserts					
Braces					
Cane					
Crutches					
Walker					
Wheelchair					

Have you ever received physical therapy? _____Yes _____No
Have you ever received occupational therapy? _____Yes _____No

Have you ever had any surgery on your hands? _____Yes _____No
On your feet? _____Yes _____No

If yes, please check which type of surgery.

__Tendon transfers (hands)
What year? _____
What side? _____Right _____Left _____Both
Which tendons were transferred? _____ _____Don't Know
Did the surgery help your condition? _____Yes _____No
Did the surgery make your condition worse? _____Yes _____No

__Finger fusions
What year?_____
What side? _____Right _____Left _____Both
Which fingers were fused? _____ _____Don't Know
Did the surgery help your condition? _____Yes _____No
Did the surgery make your condition worse? _____Yes _____No

__Carpal tunnel surgery
What year?_____
What side? _____Right _____Left _____Both
Did the surgery help your condition? _____Yes _____No
Did the surgery make your condition worse? _____Yes _____No

__Other hand surgeries, please describe
What year?_____
What side? _____Right _____Left _____Both
Did the surgery help your condition? _____Yes _____No
Did the surgery make your condition worse? _____Yes _____No

__Ankle fusion
What year?_____
What side? _____Right _____Left _____Both
Did the surgery help your condition? _____Yes _____No
Did the surgery make your condition worse? _____Yes _____No

__Tendon transfers (feet)
What year? _____
What side? _____Right _____Left _____Both
Which tendons were transferred? _____ _____Don't Know
Did the surgery help your condition? _____Yes _____No
Did the surgery make your condition worse? _____Yes _____No

__Triple arthrodesis
What year?_____
What side? _____Right _____Left _____Both
Did the surgery help your condition? _____Yes _____No
Did the surgery make your condition worse? _____Yes _____No

__Other foot surgeries, please describe
What year?_____
What side? _____Right _____Left _____Both
Did the surgery help your condition? _____Yes _____No
Did the surgery make your condition worse? _____Yes _____No

Please respond to the following:

At the present time, I have foot pain:
__ never
__only with heavy activity
__only at the end of the day
__with routine daily activities

At the present time, ankle sprains are:
__rarely a problem
__occasionally a problem with sports
__a problem with routine daily activities

At the present time, finding comfortable shoes is:
__not a problem
__a problem but I can find them
__impossible

I am having enough foot problems that I would consider surgical treatment options:
__Yes
__no

Is your sensation (sense of feeling) abnormal? _____Yes _____No _____ Don't Know
If yes, check the items that apply
___Have you ever stepped on a sharp object without feeling pain?
___Have you ever cut yourself without feeling pain?
___Have you ever burned yourself without feeling pain?
___Do you have pins & needles sensation?
___Do you have burning pain?

Please check all areas where you have abnormal sensation

___Right arm ___Left arm
___Right leg ___Left leg
___Right hand ___Left hand
___Right foot ___Left foot

Do you have difficulty hearing? _____Yes _____No

Do you often get short of breath? _____Yes _____No
If yes, is there a physician who has evaluated you, or is treating you for this problem? ____Yes ____No

Do you drink alcohol? _____Yes _____No
If yes, complete below
Beer, _____cans/week
Wine, _____glasses/week
Hard alcohol, _____shots/week
Mixed drink, _____drinks/week

Do you smoke cigarettes? _____Yes _____No
If yes, how many packs per day? _____
How many packs per week? _____

Please check all other health problems that you have:

___Diabetes
___Inflammatory Neuropathies
___Guillain-Barre Syndrome
___Chronic Inflammatory Polyradiculoneuropathy (CIDP)
___Cancer, please specify type _____
___HIV
___Lupus, Rheumatoid Arthritis or Collagen Vascular Disease
___Crohns, Celiac Disease or Ulcerative Colitis
___Sarcoidosis
___Kidney disease and/or dialysis
___Lung Disease
___Thyroid Disorder: _____
___Other, please specify: _____

Please choose the description below that you feel best describes your daily activities of living style.

— 100%. Completely independent. Able to do all activities without slowness, difficulty or impairment. Essentially normal activity, unaware of any difficulty.

— 90%. Completely independent. Able to do all activities with some degree of slowness, difficulty or impairment. Might take twice as long, beginning to be aware of difficulty.

— 80%. Completely independent in most activities. Takes twice as long, conscious of difficulty and slowness.

— 70%. Not completely independent. More difficulty with some activities. 3 to 4 times as long in some.

— 60%. Some dependency. Can perform most activities, but with exceeding slowness and much effort.

— 50%. More dependent. Help with half, slower, etc. Difficulty with everything.

— 40%. Very dependent. Can assist in all activities, but few alone.

— 30%. With effort, now and then does a few activities alone or begin alone. Much help needed.

— 20%. Nothing alone. Can be a slight help in some activities. Severe invalid.

— 10%. Totally dependent, helpless. Complete invalid. Care impossible outside hospital setting.

— 0%. Basic bodily functions only. Bedridden.

SECTION E: MEDICATIONS

Use the following tables, to document medication events and medications you have taken or currently take. Indicate how long each medication was taken and its effect on CMT using the follow following codes.

Length of time:
1 = less than 1 month
2 = one month to 1 year
3 = more than 1 year
4 = don't know
5 = one time
6 = one to 5 times
7 = more than 5 times

Effect on CMT:
B – made it better
W – made it worse
N – no effect
DK – don't know

Please use the codes on preceding page to complete this table.

Name of Medication	**Length of time**	**Effect on CMT**
Have you ever experienced the following medication events:	**Use Codes (4-7)**	**(B, W, N, DK)**
Anesthesia for surgery		
Epidural		
Nitrous oxide (chronic repeated inhalation)		
List all other medication events:		
Have you ever taken the following Medications:	**Use Codes (4-7)**	**(B, W, N, DK)**
Adriamycin		
Amiodarone		
Choramphenicol		
Cisplatin		
Dapsone		
Diphenylhydantoin (Dilantin)		
Disulfiram (Antabuse)		
Glutethimide (Doriden)		
Gold		
Hydralazine (Apresoline)		
Isoniazid (INH)		
Lithium		

Megadoses of vitamin A*		
Megadoses of vitamin B6* (Pyridoxine)		
Megadoses of vitamin D*		
Misomidazole		
Metronidazole (Flagyl)		
Nitrofurantoin (Furadantin Macrodantin)		
Penicillin (large IV doses only)		
Perhexiline (Pexid)		
Taxol		
Vincristine		
Zoloft		
*** megadose = ten or more times the recommended daily allowance**		
Other prescription medications you currently take:	**Use Codes (4-7)**	**(B, W, N, DK)**
Over-the-counter medications (vitamins, herbs, etc.) you take:	**Use Codes (4-7)**	**(B, W, N, DK)**

Thank you for taking the time to complete this questionnaire.