INC 6601 – Minimal Data Set – Visit Information

Protocol Number: Participant ID:
Site: Date of Visit:
Person Completing Form:

First Visit Information (Subsequent visits: update if changed)

Family History

1. Affected Family Members:				
	☐	Consanguinity	☐	Male to Male Transmission
	☐	Parents	☐	Children
	☐	Siblings	☐	Unknown
	☐	Other: _____		

# of Affected Family Members (not including proband):	_____
Notes:	_____ _____ _____

Developmental History

1. Walked before 15 Months:	○	Yes	○	No	○	Unknown
Notes:	_____ _____ _____					

2. Foot Deformity:	○	Yes	○	No	○	Unknown
If Yes:	☐	Pes planus	☐	Pes cavus		
	☐	Hammertoes	☐	Other:	_____ _____	

3. Foot Surgery:	○	Yes	○	No	○	Unknown
Procedures involved:	☐	Bone	☐	Soft Tissue		

☐	Tendon transfer	Age:	_____
☐	Achilles tendon lengthening	Age:	_____
☐	Ankle joint fusion	Age:	_____
☐	Osteotomy	Age:	_____
☐	Toes Straightened	Age:	_____
☐	Other: _____	Age:	_____

Notes:	_____ _____ _____

4. Hand Surgery:	○	Yes	○	No	○	Unknown
Procedures Involved:	☐	Bone	☐	Soft Tissue		

☐	Tendon transfer	Age:	_____	Side:	○	R	○	L	○	B
☐	Carpel Tunnel	Age:	_____	Side:	○	R	○	L	○	B
☐	Other: _____			Age:	_____					

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5. Scoliosis:	○	Yes	○	No	○	Unknown
If Yes:	○	Surgery		Age:	_____	
	○	Bracing		Age:	_____	
6. Hip Dysplasia:	○	Yes	○	No	○	Unknown
If Yes; Age:					_____	
7. Sural Nerve Biopsy:	○	Yes	○	No	○	Unknown
Tissue available:	○	Yes	○	No	○	Unknown
Other Registries:	_____					

Current Visit Information (Fill out this information at every visit, including first visit)

Walking Ability

1. Difficulty walking:	○	Yes	○	No	○	Unknown
If Yes; Age:					_____	
2. Difficulties with balance:	○	Yes	○	No	○	Unknown
If Yes; Age:					_____	
3. Orthotic aids:	○	Yes	○	No	○	Unknown
If Yes; Age:					_____	
If Yes:	○	Shoe inserts	○	Ankle-foot orthotics	○	Other: _____
4. Walking support needs:	○	Yes	○	No	○	Unknown
If Yes:	○	Unilateral (single cane or "stick" holding one's arm)			Age:	_____
	○	Bilateral (two canes, Zimmer frames, walkers)			Age:	_____
5. Wheelchair use required:	○	Yes	○	No	○	Unknown
If Yes:	○	Intermittent use			Age:	_____
	○	Regular use			Age:	_____

Hand Function

1. Difficulties with:						
Buttons / zippers / fasteners / bottles:	○	Yes	○	No	○	Unknown
Eating utensils:	○	Yes	○	No	○	Unknown

Strength

Use MRC Scale: 5; 4+, 4, 4-; 3; 2; 1; 0.

	Left		Right					
First Dorsal Interosseous	_____		_____		☐	Unknown	☐	Prior Surgery
Foot Dorsi flexion:	_____		_____		☐	Unknown	☐	Prior Surgery
Foot Plantar flexion:	_____		_____		☐	Unknown	☐	Prior Surgery

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Sensation (>50% of time)

1. Burning or tingling in feet or hands:	○	Yes	○	No	○	Unknown
2. Decreased ability to feel:	○	Yes	○	No	○	Unknown
3. Ulcerations in feet or hands:	○	Yes	○	No	○	Unknown
4. Amputations feet or hands:	○	Yes	○	No	○	Unknown
5. Arthritic-like (aching) pain:	○	Yes	○	No	○	Unknown

If Yes:	☐	Ankles	☐	Knees
	☐	Hips	☐	Unknown
	☐	Other:		_____ _____ _____

Optic Nerve Atrophy

1. Optic Nerve Atrophy:	○	Yes	○	No	○	Unknown

Hearing Loss

1. Hearing loss:	○	Total	○	Partial	○	No	○	Unknown

Neurophysiology

Motor Nerve Conduction Velocity (m/s):	○	Unknown	Ulnar:	_____	Median:	_____
	○	No response				
F-wave Latency (ms):	○	Unknown	Ulnar:	_____	Median:	_____
	○	No response				
CMAP Amplitude (mV):	○	Unknown	Ulnar:	_____	Median:	_____
	○	No response				

SNAP amplitudes (µV):

	Ulnar:	_____	○	Orthodromic	○	Antidromic	○	Unknown
			○	No response				
	Median:	_____	○	Orthodromic	○	Antidromic	○	Unknown
			○	No response				
	Radial:	_____	○	Orthodromic	○	Antidromic	○	Unknown
			○	No response				

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Scoring Systems

1. Scoring systems:		☐	Unknown
	CMT Neuropathy Score – 2nd ed (CMTNS-2):	_____	
	CMT Exam Score – 2nd ed (CMTES-2):	_____	
	CMT Pediatric Scale – age group: 4-21 years (CMTPS):	_____	