For Study Use Only. Please do not write in this section.	
SITE ID: INDIVIDUAL ID:	
PHYSICIAN:	YEAR OF VISIT:

PATIENT HISTORY QUESTIONNAIRE

Instructions: Please take a moment to read these instructions before completing the Patient History Questionnaire for the Peripheral Neuropathy Research Registry (PNRR).

- Be sure to read each question carefully and answer as thoroughly as possible.
- If you are unsure how to fill out any part of this questionnaire, please do not hesitate to ask for help and guidance.

Section I. PATIENT INFORMATION

What year were you born?	
What is your sex?	Male
	E Female
Are you Hispanic or Latino?	☐ Yes
	□ No
What is your race? Mark <u>only</u> one.	
🗌 American Indian / Alaska Native	Native Hawaiian or other Pacific Islander
Asian	White
Black or African American	More than one race

When did you notice your first symptoms associated with peripheral neuropathy?

Section II. CURRENT SYMPTOMS

- Please provide answers to these questions regarding **symptoms due to your peripheral neuropathy** only (e.g., pain, numbness, tingling, burning, weakness, balance, etc).
- Please refer to your 'average' pain during the **past 7 days**. Do not refer to any extreme levels of pain such as 'most' painful or 'least' painful.
- 1. PAIN: Do you have pain or painful discomfort from your polyneuropathy?
 - Yes
 - No ► If you do <u>NOT</u> have pain, skip to **Question 2** (on Page 6).

a. Where is your pain located? Mark <u>all</u> areas that apply.

Left foot	Right foot
Left leg	🗌 Right leg
☐ Left arm	🗌 Right arm
Left hand	🗌 Right hand
Torso/ trunk	Face
Back	Neck

b. Is your pain:

Always present	
----------------	--

Sometimes present

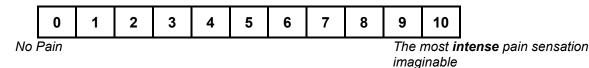
Don't know

c. How long ago did your pain start?

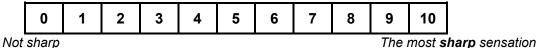
Within the last week	☐ 1 to 5 <u>years</u> ago
2 to 4 <u>weeks</u> ago	☐ 6 to 10 <u>years</u> ago
☐ 1 to 6 <u>months</u> ago	☐ 11 to 20 <u>years</u> ago
☐ 7 to 12 <u>months</u> ago	🗌 As long as I can remember

For the next set of questions, place an "X" through the number that best describes your pain.

d. Please use the scale below to tell us how intense your pain is.

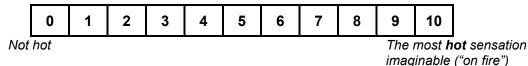


e. Please use the scale below to tell us how <u>sharp</u> your pain feels. Words used to describe sharp feelings include "like a knife," like a spike," "jabbing," "or like jolts."

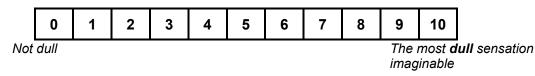


imaginable ("like a knife")

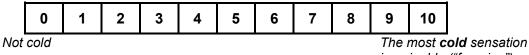
f. Please use the scale below to tell us how <u>hot</u> your pain feels. Words used to describe very hot pain include "burning" and "on fire."



g. Please use the scale below to tell us how <u>dull</u> your pain feels. Words used to describe very dull pain include "like a dull toothache," "dull pain," "aching," and "like a bruise."

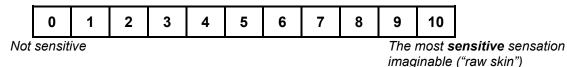


h. Please use the scale below to tell us how <u>cold</u> your pain feels. Words used to describe very cold pain include "like ice" and "freezing."



imaginable ("freezing")

i. Please use the scale below to tell us how <u>sensitive</u> your skin is to light touch or clothing. Words used to describe sensitive skin include "like sunburned skin" and "raw skin."



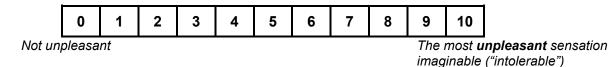
j. Please use the scale below to tell us how <u>itchy</u> your pain feels. Words used to describe itchy pain include "like poison oak" and "like a mosquito bite."

	0	1	2	3	4	5	6	7	8	9	10	
Not	itchy									The I	most it	ch

The most **itchy** sensation imaginable ("like poison oak")

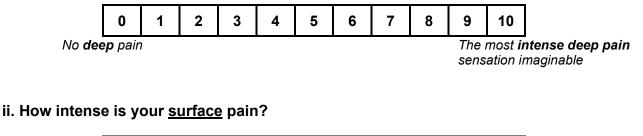
FOR STUDY USE ONLY	SITE ID:	_ INDIVIDUAL ID:				
k. Which of the following statements best describes the <u>time quality</u> of your pain?						
I feel a background pain <u>all the time</u> and occasiona	al flare-ups (brea	k-through pain) <u>some of the time</u> .				
Describe the background pain:						
Describe the flare-up (break-through) pain:						
☐ I feel a single type of pain <u>all the time</u> . Describe this pain:						
☐ I feel a single type of pain only <u>sometimes</u> . Other ti Describe this occasional pain:	imes I am pain fr	ee.				

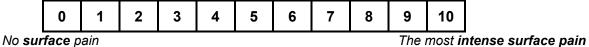
I. Now that you have told us the different physical aspects of your pain, the different types of sensations, we want you to tell us overall how <u>unpleasant</u> your pain is to you. Words used to describe very unpleasant pain include "miserable" and "intolerable." Remember, pain can have a low intensity, but still feel extremely unpleasant, and some kinds of pain can have a high intensity but be very tolerable. With this scale, please tell us how <u>unpleasant</u> your pain feels.



m. We want you to give us an estimate of the severity of the <u>deep</u> versus <u>surface</u> pain. We want you to rate both locations of pain (deep and surface) separately. We realize this can be difficult to make these estimates, and most likely it will be a "best guess," but please give us your best estimate.

i. How intense is your deep pain?





sensation imaginable

n. Do you experience abnormal perceptions of pain or discomfort from a normally non-painful stimulus? For example, do you experience tingling, burning, discomfort or some other abnormal sensation when lightly touched?

Yes
103

🗌 No

Don't know

o. Are you taking medication for your neuropathic pain?

Yes

🗌 No	► If you c	lo <u>NOT</u> take r	nedication, skip to	D Question 2	(next Pa	age).
------	------------	----------------------	---------------------	--------------	----------	-------

p. How efficient is your pain medication?

- Not effective
- Somewhat effective
- ☐ Very effective
- Was once effective but no longer helps

q. Does your pain medication have any side effects?

Sleepiness	drowsiness	(somnolence)
Siechiness,	ulowsiness	(sommolence)

- Dizziness
- U Weight gain
- Nausea, upset stomach
- Sexual dysfunction
- Other: _____

No side e	ffects
-----------	--------

r. Have you taken other medications for your neuropathic pain in the past? If so, please tell us why you discontinued to take those medications:

Name of medication	Dosage of medication	Reason(s) you stopped / switched
		 Side effects Insurance coverage No longer effective Other:
		 Side effects Insurance coverage No longer effective Other:
		 Side effects Insurance coverage No longer effective Other:

For the following questions, please refer only to those symptoms you have experienced due to your peripheral neuropathy during the past 7 days.

2. NUMBNESS: Do you have numbness (loss of sensation)?

Yes

 \square No \blacktriangleright If you do <u>NOT</u> have numbress, skip to **Question 3**.

a. Where is your numbness (loss of sensation) located? Mark <u>all</u> areas that apply.

Left foot	Right foot
Left leg	🗌 Right leg
☐ Left arm	🗌 Right arm
Left hand	🗌 Right hand
Torso/ trunk	E Face
Back	Neck

b. Is your numbness (loss of sensation):

Always present

Sometimes present

Rarely present

Don't know

FOR STUDY USE ONLY	SITE ID: INDIVIDUAL ID:
c. How long ago did your numbness (loss o	of sensation) start?
Within the last week	☐ 1 to 5 <u>years</u> ago
2 to 4 <u>weeks</u> ago	☐ 6 to 10 <u>years</u> ago
☐ 1 to 6 <u>months</u> ago	☐ 11 to 20 <u>vears</u> ago
☐ 7 to 12 <u>months</u> ago	As long as I can remember

3. Do you experience <u>spontaneous</u> abnormal sensations (with or without loss of sensation)? Some people might describe these as "pins and needles," "tingling," or "like part of a limb fell asleep."

Yes,	all	the	time	

Yes, occasionally

No, never

For the following questions, please refer only to those symptoms you have experienced due to your peripheral neuropathy during the past 7 days.

4. WEAKNESS: Do you have weakness (loss of strength or power)?

Yes

□ No ► If you do <u>NOT</u> have weakness, skip to **Question 5.**

a. What is your weakness (loss of strength or power)? What are the types of activities you have difficulty with? Mark <u>all</u> that apply.

E Feet and ankles (t	rip easily)
----------------------	-------------

Foot drop

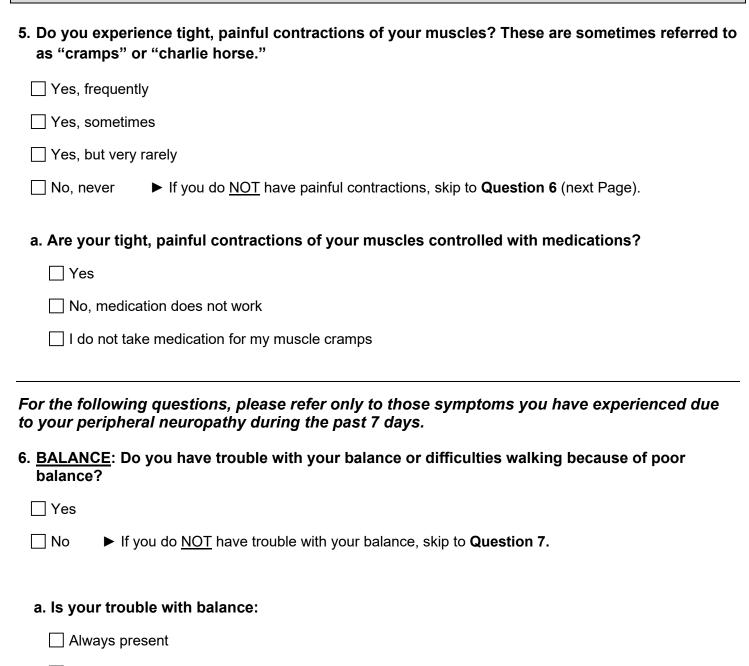
Proximal legs (difficulty going upstairs, getting out of a chair or toilet)

Fine motor tasks with hands (difficulty buttoning, zipping a zipper)

Decreased grip strength

Proximal arms (difficulty lifting heavy objects, shampooing hair)

Other:



Sometimes present

Rarely present

Don't know

b. Do you use any assistive devices when walking? Mark <u>all</u> that apply.

Yes, I use a walker	Yes, I use orthotics
Yes, I use a wheelchair	Yes, I use a cane
🗌 No, I am bedbound	☐ No, I do not use any assistive devices when walking

c. Have you had any falls?	
Yes, almost every day	Yes, more than once over the last year
Yes, more than once a week	Yes, less than once per year
Yes, about once per month	□ No, I have not fallen

7. <u>AUTONOMIC</u>: Now we want to know a little bit about your autonomic system. Your autonomic system regulates things like heart rate, blood pressure, sweating, bowel function, and sexual function.

a. Do you experience spells of lightheadedness or dizziness as if you were going to faint?

🗌 Yes	
🗌 No	► If you do <u>NOT</u> have dizziness, skip to Question 7b (next Page).

i. Do your spells of lightheadedness or dizziness get worse after the following activities? Mark <u>all</u> that apply.

After standing up quickly	After a hot bath or shower
After standing for a long time	After a large meal
Other:	

ii. Have you ever fainted or "passed out"?

Yes, at least once per month	Yes, less than once per year
Yes, several times per year	Yes, but very rarely

Yes, about once per year

No, I have never fainted

7b. Do you have abnormal sweating? Mark <u>all</u> that apply.

	Yes,	I swea	t <u>more</u>	after	eating
--	------	--------	---------------	-------	--------

Yes, I sweat less in a warm environment

☐ Yes, I have other abnormal sweating, please explain: _____

🗌 No

c. Do you experience dryness of your eyes or mouth?

Yes

🗌 No

d. Do you have abnormal bowel movements? Mark <u>all</u> that apply.

- Yes, I have diarrhea
- Yes, I have constipation
- 🗌 No

e. Do you have difficulties with urination? Mark <u>all</u> that apply.

- Yes, I often experience a sudden, immediate need to go to the bathroom (urgency)
- Yes, I have the urge to go to the bathroom frequently (frequency)
- Yes, I lose control of my bladder (incontinence)
- Yes, I have trouble emptying my bladder or initiating urination
- No, I don't have difficulties with urination

f. MEN ONLY: Has your sexual function changed recently? Mark <u>all</u> that apply.

- Yes, I have been having difficulties having erections
- Yes, I have been having difficulties having ejaculation

🗌 No

For the following questions, please refer only to those symptoms you have experienced due to your peripheral neuropathy during the past 7 days.

- 8. SLEEP: Have you experienced sleeping difficulties?
 - 🗌 Yes
 - □ No If you do \underline{NOT} have sleeping difficulties, skip to **Question 9**.
 - a. Do you have difficulty falling asleep or staying asleep at night from pain due to your peripheral neuropathy?

🗌 Yes

🗌 No

- b. Do you have an urge to move your legs at night, accompanied or caused by unpleasant sensations?
 - 🗌 Yes

🗌 No

- c. Are your sleeping difficulties controlled with medications?
 - 🗌 Yes

□ No, medication does not work

I do not take sleep aid medication

9. Which symptom bothers you the most? Please mark only one.

🗌 Pain	
Numbness (loss of sensation))

- Weakness (loss of strength or power)
- Balance or difficulty with walking
- Other _____

Section III. MEDICATIONS, VITAMINS, AND SUPPLEMENTS

Please list all medications, vitamins, and supplements that you are *currently* taking.

Medication, Vitamin, or Supplement	Dosage
e.g., Aspirin	325 mg once a day

Section IV. MEDICAL HISTORY

10. Please mark all that apply:	
 Amyloidosis Anorexia Cancer Have you ever received chemotherapy? Yes No Don't know 	 HIV Have you ever received ddl, d4T, or DDC? Yes No Don't know Have you ever received protease inhibitor? Yes No Don't know
Name of drug(s): Cardiac disease Celiac disease Crohn's disease Diabetes Mellitus Type I Type II Elevated cholesterol Elevated triglycerides Fibromyalgia Hepatitis Hepatitis B Hepatitis C Have you ever received Interferon treatments? Yes	 Irritable bowel disease Kidney disease Leprosy Liver disease Lyme disease Mixed connective tissue disease Peripheral vascular disease Rheumatoid arthritis Sarcoidosis Scleroderma Shingles Sjögren's syndrome Syphilis Systemic lupus erythematosus (SLE) Thyroid disease Hyper Hypo Don't know Ulcerative colitis Vitamin B1 deficiency Vitamin B6 deficiency
	 Vitamin B6 over-dose Vitamin B12 deficiency

11. Did you have any vaccinations, infections, or the flu <u>1 to 3 months</u> before the onset of your neuropathy?

Yes, I had the flu	
Yes, I had an infection(s)	► If YES , which one(s)?
Yes, I had a vaccination(s)	► If YES , which one(s)?
□ No	
🗌 Don't know	

12. If you have other medical or infectious conditions, please list below:

1	
2	
3.	
4	

13. If you have had major surgery, please list the type of surgery and when it was performed:

1	What year?
2	What year?
3	What year?
4	What year?
5	What year?
6	What year?

14. As a child, did you have difficulties or delays in development?

- 🗌 Yes
- \square No \blacktriangleright If you did <u>NOT</u> have delays, skip to **Section V**.

a. As a child did you have difficulty with (mark <u>all</u> that apply):

- Riding a bicycle
- Roller skating/ice skating
- Running
- $\hfill\square$ Keeping up with peers in physical activities
- Don't know

b. At what age did you begin having developmental delays? _____ (years)

Section V. SOCIAL AND OCCUPATIONAL HISTORY

15. What is your current occupation?	
16. What is your past occupation?	
17. Have you had (now or in the past) any occupational e hazardous chemicals? Mark <u>all</u> that apply.	exposure to <u>excessive</u> amounts of
Yes, herbicides, pesticides or fungicides	
► If YES, which one(s)?	
Yes, heavy metals , such as lead, mercury, arsenic or o	thers
► If YES, which one(s)?	
Yes, solvents such as N-hexane, perchloroethylene, tri	chloroethylene, carbon disulfide or others
► If YES, which one(s)?	
🗌 No	
18. Have you <u>ever</u> smoked? If you have <u>never</u> smoked, r □ Yes, I <u>currently</u> smoke ▶ If YES, how many <u>packs per day</u> ? △ Less than 1 pack ○ More than 1 pack □ Yes, I have smoked in the past, but I do not currently smo ▶ If YES, how many <u>packs per day</u> ? ▲ More than 1 pack ○ More than 1 pack	For how many <u>years</u> ? Less than 10 years More than 10 years ke For how many <u>years</u> ? Less than 10 years More than 10 years More than 10 years
 19. Have you <u>ever</u> drunk alcohol? If you have <u>never</u> drunk Question 20 (on page 14). For this question, one drink is beer, or one mixed drink. Yes, I <u>currently</u> drink 	-
► If YES, how many drinks <u>per day</u> ? AND □ Less than 2 drinks □ More than 2 drinks	For how many <u>years</u> ? <u>Less</u> than 10 years <u>More</u> than 10 years

FOR STUDY USE ONLY	SITE ID: INDIVIDUAL ID:
Yes, I have drunk alcohol <u>in the past</u> , but I do <u>not</u> c	currently drink
	AND For how many <u>years</u> ?
☐ <u>Less</u> than 2 drinks	Less than 10 years
More than 2 drinks	☐ <u>More</u> than 10 years
At what age did you <u>stop</u> drinki	ing? years
20. Have you <u>ever</u> used recreational drugs? If you and skip to Question 21. For this question, "recreate psychoactive rather than medical purpose, such as m	tional drugs" refer to any drugs taken for a
Yes, I <u>currently</u> use recreational drugs	
► If YES, which drug(s) do you use? A	AND For how many <u>years</u> ?
	☐ <u>Less</u> than 10 years ☐ <u>More</u> than 10 years
□ Vac these used recreational draws in the rest had	
Yes, I have used recreational drugs <u>in the past</u> , but ► If YES, which drug(s) did you use?	AND For how many <u>years</u> ?
	$\Box \underline{\text{Less}} \text{ than 10 years}$
	☐ <u>More</u> than 10 years
At what age did you <u>stop</u> using recreation	
21. What is your marital status?	
Single Separated	
Married Divorced	
☐ Widowed	
22. Which best describes your living situation?	
I live alone.	
I live with my spouse/ partner.	
I live with my parent(s)/ sibling(s).	
I live with a roommate.	
I live with my children.	

Section VI. FAMILY HISTORY

23. Do you have any family members with peripheral neuropathy?

Yes

□ No ► If you did <u>NOT</u> have any family members with peripheral neuropathy, skip to **Question 24.**

□ Don't know ► Skip to **Question 24**.

Please tell us more about your family members with peripheral neuropathy. In the table below, list their relationship to you, type of neuropathy, and the age at which they were diagnosed with peripheral neuropathy. *See example.*

Relationship to you	Type of neuropathy	Age at diagnosis
e.g., Maternal Grandmother	Diabetic neuropathy	68

24. Do you have any family members with <u>autoimmune disease</u>? Examples of autoimmune diseases include rheumatoid arthritis, vasculitis, systemic lupus erythematosis, Sjögren's disease, Hashimoto's thyroiditis, ulcerative colitis, and Crohn's disease.

🗌 Yes

□ No ► If you did <u>NOT</u> have any family members with autoimmune disease, skip to **Question 25**.

□ Don't know ► Skip to **Question 25**.

Please tell us more about your family members with autoimmune disease. In the table below, list their relationship to you, type of autoimmune disease, and the age at which they were diagnosed with autoimmune disease. See example.

Relationship to you	Type of autoimmune disease	Age at diagnosis
e.g., Brother	Vasculitis	45

25. Do you have any family members with the following diseases or conditions: DIABETES, HIGH TRIGLYCERIDES, HIGH CHOLESTEROL?

☐ Yes

□ No ► If you did <u>NOT</u> have any family members with these diseases/ conditions, skip to **Question 26.**

□ Don't know ► Skip to **Question 26**.

Please tell us more about your family members with these diseases / conditions. In the table below, list their relationship to you, type of disease/ condition, and the age at which they were diagnosed with that disease or condition. *See example.*

Relationship to you	Type of disease/ condition	Age at diagnosis
e.g., Maternal Grandmother	Diabetes AND High cholesterol	60

26. Do you have any other family history of disease?

🗌 Yes

🗌 No

Don't know

Please tell us more about your family history of disease. In the table below, list their relationship to you, type of disease, and the age at which they were diagnosed with that disease. See example.

Relationship to you	Type of disease	Age at diagnosis
e.g., 2 Paternal Aunts	Breast cancer	37 and 42

SITE ID: ____ INDIVIDUAL ID: ____

Section VII. EXERCISES

Please tell us about your exercise habits in the past two weeks.

If you select Other, please let us know the type of exercises you perform.

Activity Type:	How many times in the past two weeks did you:	On average, how many minutes per occasion:	How intense would you rate the effort:		
Aerobic Exercises					
Walking (for exercise) or hiking	Times	Minutes	□ Low	□ Moderate	□ High
Jogging or running (including treatmill)	Times	Minutes	□ Low	□ Moderate	□ High
Cycling, including stationary bike	Times	Minutes	□ Low	□ Moderate	□ High
Fitness classes (Barre, CorePower)	Times	Minutes	□ Low	□ Moderate	□ High
Water Aerobics	Times	Minutes	□ Low	□ Moderate	□ High
Swimming	Times	Minutes	□ Low	□ Moderate	□ High
Stairmaster	Times	Minutes	□ Low	□ Moderate	□ High
Thai Chi	Times	Minutes	□ Low	□ Moderate	□ High
Other:	Times	Minutes	□ Low	□ Moderate	□ High
Other:	Times	Minutes	□ Low	□ Moderate	□ High
Anaerobic Exercises					
Golf	Times	Minutes	□ Low	□ Moderate	□ High
Stretching	Times	Minutes	□ Low	□ Moderate	□ High
Yoga or Pilates	Times	Minutes	□ Low	□ Moderate	□ High
Weight lifting and weight training	Times	Minutes	□ Low	□ Moderate	□ High
Gardening and yard work	Times	Minutes	□ Low	□ Moderate	□ High
Other:	Times	Minutes	□ Low	□ Moderate	□ High

THANK YOU for filling out the PNRR Questionnaire!