For Study Use Only. Please do not write in this section.

SITE ID: _____ INDIVIDUAL ID: _____

PHYSICIAN: _____ YEAR OF VISIT: _____
YYYY

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

☐ Female

Are you Hispanic or Latino?

☐ Yes

☐ No

What is your race? Mark only one.

☐ American Indian / Alaska Native

☐ Asian

☐ Black or African American

☐ Native Hawaiian or other Pacific Islander

☐ White

☐ 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 NOT have pain, skip to **Question 2** (on Page 6).

a. Where is your pain located? Mark all 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
☐ Rarely present
☐ Don't know

c. How long ago did your pain start?

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

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

d. Please use the scale below to tell us how **<u>intense</u>** your pain is.

0	1	2	3	4	5	6	7	8	9	10

No Pain — *The most **intense** pain sensation imaginable*

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."

0	1	2	3	4	5	6	7	8	9	10

Not sharp — *The most **sharp** sensation 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."

0	1	2	3	4	5	6	7	8	9	10

Not hot — *The most **hot** sensation imaginable ("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."

0	1	2	3	4	5	6	7	8	9	10

Not dull — *The most **dull** sensation imaginable*

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."

0	1	2	3	4	5	6	7	8	9	10

Not cold — *The most **cold** sensation 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."

0	1	2	3	4	5	6	7	8	9	10

Not sensitive — *The most **sensitive** sensation imaginable ("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 most **itchy** sensation imaginable ("like poison oak")*

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** occasional flare-ups (break-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 times I am pain free.

Describe this occasional pain: _____

_____

l. 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.

0	1	2	3	4	5	6	7	8	9	10

Not unpleasant — *The most **unpleasant** sensation imaginable ("intolerable")*

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 <u>deep</u> pain?

0	1	2	3	4	5	6	7	8	9	10

*No **deep** pain* — *The most **intense deep pain** sensation imaginable*

ii. How intense is your <u>surface</u> pain?

0	1	2	3	4	5	6	7	8	9	10

*No **surface** pain* — *The most **intense surface 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

☐ No

☐ Don't know

o. Are you taking medication for your neuropathic pain?

☐ Yes

☐ No ► If you do NOT take medication, skip to **Question 2** (next Page).

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)

☐ Dizziness

☐ Weight gain

☐ Nausea, upset stomach

☐ Sexual dysfunction

☐ Other: _____

☐ No side effects

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

☐ No ► If you do NOT have numbness, skip to **Question 3**.

a. Where is your numbness (loss of sensation) located? Mark all 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 numbness (loss of sensation):

☐ Always present

☐ Sometimes present

☐ Rarely present

☐ Don't know

c. How long ago did your numbness (loss of sensation) start?

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

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3. Do you experience spontaneous 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 NOT 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 all that apply.

- ☐ Feet and ankles (trip 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: _____

5. Do you experience tight, painful contractions of your muscles? These are sometimes referred to as "cramps" or "charlie horse."

☐ Yes, frequently

☐ Yes, sometimes

☐ Yes, but very rarely

☐ No, never ► If you do NOT have painful contractions, skip to **Question 6** (next Page).

a. Are your tight, painful contractions of your muscles controlled with medications?

☐ Yes

☐ No, medication does not work

☐ I do not take medication for my muscle cramps

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

6. BALANCE: Do you have trouble with your balance or difficulties walking because of poor balance?

☐ Yes

☐ No ► If you do NOT have trouble with your balance, skip to **Question 7.**

a. Is your trouble with balance:

☐ Always present

☐ Sometimes present

☐ Rarely present

☐ Don't know

b. Do you use any assistive devices when walking? Mark all 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 a week
- ☐ Yes, about once per month
- ☐ Yes, more than once over the last year
- ☐ Yes, less than once per year
- ☐ No, I have not fallen

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7. AUTONOMIC: 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 NOT have dizziness, skip to **Question 7b** (next Page).

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

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

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

- ☐ Yes, at least once per month
- ☐ Yes, several times per year
- ☐ Yes, about once per year
- ☐ Yes, less than once per year
- ☐ Yes, but very rarely
- ☐ No, I have never fainted

7b. Do you have abnormal sweating? Mark all that apply.

- ☐ Yes, I sweat more 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 all that apply.

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

e. Do you have difficulties with urination? Mark all 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 all 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 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

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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
  Name of drug(s): _____
  _____
- ☐ Cardiac disease
- ☐ Celiac disease
- ☐ Crohn's disease
- ☐ Diabetes Mellitus
  - ☐ Type I
  - ☐ Type II
- ☐ Elevated cholesterol
- ☐ Elevated triglycerides
- ☐ Fibromyalgia
- ☐ Hepatitis
  - ☐ Hepatitis A
  - ☐ Hepatitis B
  - ☐ Hepatitis C

  Have you ever received Interferon treatments?
  ☐ Yes ☐ No ☐ Don't know
- ☐ HIV
  Have you ever received ddI, d4T, or DDC?
  ☐ Yes ☐ No ☐ Don't know
  Have you ever received protease inhibitor?
  ☐ Yes ☐ No ☐ Don't know
- ☐ 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

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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

☐ No ► If you did NOT have delays, skip to **Section V.**

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

☐ Riding a bicycle

☐ Roller skating/ice skating

☐ Running

☐ 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 exposure to excessive amounts of hazardous chemicals? Mark all that apply.

☐ Yes, **herbicides**, **pesticides** or **fungicides**

► If **YES**, which one(s)? _____

☐ Yes, **heavy metals**, such as lead, mercury, arsenic or others

► If **YES**, which one(s)? _____

☐ Yes, **solvents** such as N-hexane, perchloroethylene, trichloroethylene, carbon disulfide or others

► If **YES**, which one(s)? _____

☐ No

---

18. Have you ever smoked? If you have never smoked, mark "No" and skip to Question 19.

☐ Yes, I currently smoke

► **If YES, how many packs per day?** **AND** **For how many years?**

☐ Less than 1 pack ☐ Less than 10 years

☐ More than 1 pack ☐ More than 10 years

☐ Yes, I have smoked in the past, but I do not currently smoke

► **If YES, how many packs per day?** **AND** **For how many years?**

☐ Less than 1 pack ☐ Less than 10 years

☐ More than 1 pack ☐ More than 10 years

At what age did you stop smoking? _____ years

☐ No

---

19. Have you ever drunk alcohol? If you have never drunk alcohol, mark "No" and skip to Question 20 (on page 14). *For this question, one drink is equal to one glass of wine, one bottle of beer, or one mixed drink.*

☐ Yes, I currently drink

► **If YES, how many drinks per day?** **AND** **For how many years?**

☐ Less than 2 drinks ☐ Less than 10 years

☐ More than 2 drinks ☐ More than 10 years

☐ Yes, I have drunk alcohol in the past, but I do not currently drink

► **If YES, how many drinks per day?** **AND** **For how many years?**

☐ Less than 2 drinks ☐ Less than 10 years

☐ More than 2 drinks ☐ More than 10 years

At what age did you stop drinking? _____ years

☐ No

---

20. Have you ever used recreational drugs? If you have never used recreational drugs, mark "No" and skip to Question 21. *For this question, "recreational drugs" refer to any drugs taken for a psychoactive rather than medical purpose, such as marijuana, cocaine, or methamphetamine.*

☐ Yes, I currently use recreational drugs

► **If YES, which drug(s) do you use?** **AND** **For how many years?**

_____ ☐ Less than 10 years

_____ ☐ More than 10 years

☐ Yes, I have used recreational drugs in the past, but I do not currently use recreational drugs

► **If YES, which drug(s) did you use?** **AND** **For how many years?**

_____ ☐ Less than 10 years

_____ ☐ More than 10 years

At what age did you stop using recreational drugs? _____ years

☐ No

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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 NOT 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 autoimmune disease? *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 NOT 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 NOT 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

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!