

GARDIAN

THE NEURONOPATHIC GAUCHER REGISTRY

OWNED AND GOVERNED BY THE GLOBAL PATIENT COMMUNITY



How do I
register to
GARDIAN



www.gardianregistry.org

GARDIAN will collect data directly from patients or caregivers. The data will be anonymized. Patients (or caregivers on behalf of patients, where applicable) must meet all of the following inclusion criteria to be eligible:

- Patient with confirmed GD3 diagnosis or primary or co-primary caregiver of a patient with a confirmed GD2 or GD3 diagnosis.
- Access to an internet-connected mobile device (e.g. smartphone, tablet) or computer with a good internet connection.
- To register, we recommend you use a tablet or computer.
- A working email account.
- Able to read and understand one of the study languages (English, French, German, Spanish, Japanese, Chinese, Arabic).
- Willing to sign an opt-in consent document indicating that the patient has been informed of all aspects of the registry.



HOW TO PARTICIPATE IN GARDIAN

If you need any help while registering please email info@gardianregistry.org.

STEP 1: Screening process: You will need approximately 20 minutes to complete this step.

Please have all information and documents to hand before you begin.

Make sure you have a good internet connection.
Click on the register link that will take you to the GARDIAN registry home page.
Choose your language.

Accept the privacy policy.
Type your email to register your account. You will receive a confirmation email.
Open the email and activate the account by clicking on the link and set a password that you can remember.

Provide your personal details such as whether you are a patient or parent or caregiver, and your date of birth.
Read and accept the informed consent.
Next step is the eligibility questionnaire.

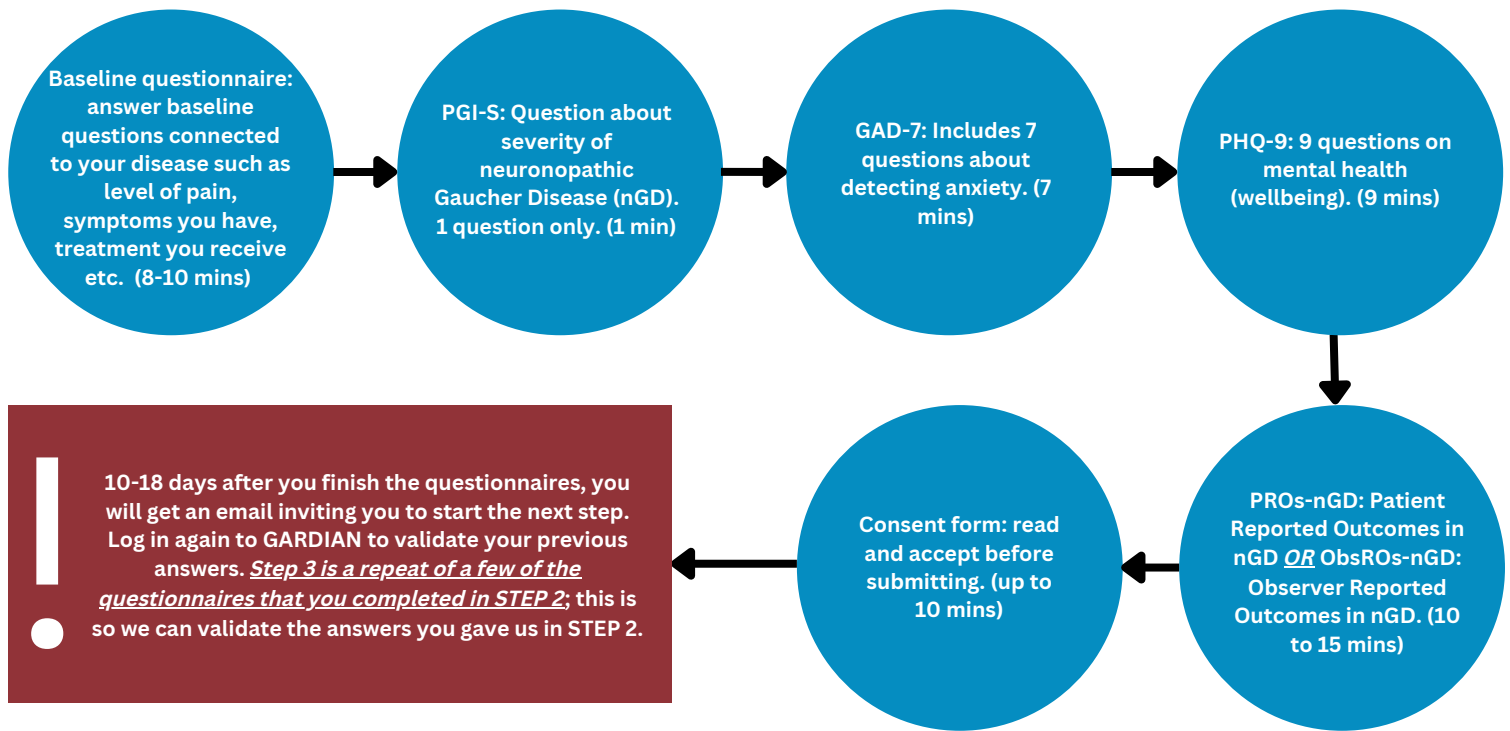
Confirmation of diagnosis: Upload one document confirming your diagnosis or that of the person you care for. It should include genotype or confirmation of clinical diagnosis from your doctor (a letter or an email). It doesn't have to be recent. It could be an old clinic letter with the details. You do not need to obtain a new document if you already have something that contains the necessary details.

Wait for an email confirmation that you are eligible and you can start answering questionnaires in GARDIAN.

This will take approximately one week.

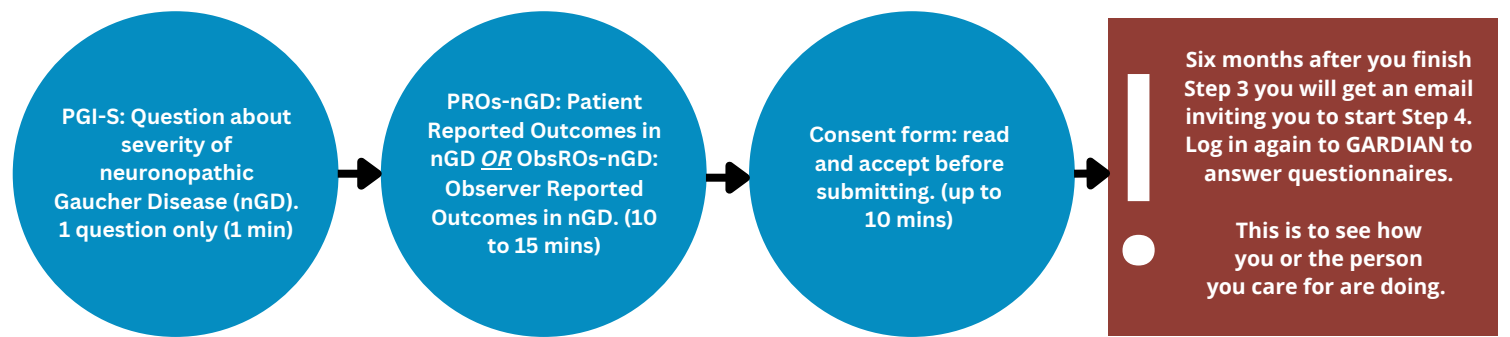
STEP 2: Questionnaires to answer: You will need approximately 50 minutes to complete this step.

First login to the registry with your email and password.
Answer a series of questionnaires related to your experience of the disease.
Once you finish one questionnaire it will go from orange to white and you can move on to the next one.



STEP 3: VALIDATION: You will need approximately 20 to 25 minutes to complete this step.

First login to the registry with your email and password.



STEP 4: Questionnaires to answer: You will need approximately 40 minutes to complete this step.

First login to the registry with your email and password.



You will need to complete all four steps over a period of six months to be fully registered.
You will be asked to complete questionnaires every six months during the life of the registry.

We truly appreciate your time and effort.
Thank you for being part of GARDIAN and helping your community!

www.gardianregistry.org

