GARDIAN FACT SHEET

THE NEURONOPATHIC GAUCHER REGISTRY

OWNED AND GOVERNED BY THE GLOBAL PATIENT COMMUNITY

BROUGHT TO YOU BY THE IGA

IN ASSOCIATION WITH

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Patient-led, owned by the IGA

Our vision is a world where all Gaucher patients have access to the treatment and care they need and there is the possibility of a cure.

Why are we doing it?

Gathering information in a standardized, consistent manner directly from a group of patients and care-givers can help to build a more detailed picture of the impact of a disease, which disease-related characteristics are important to consider, what health related outcomes are of importance to patients and caregivers and how the patient experience and care could be improved. This is particularly important in the case of ultra-rare diseases such as nGD.

Initially GARDIAN will be available in 8 languages:

- UK English • US English
- Arabic • Japanese
- Simplified Chinese
- German • Spanish
- French

As a healthcare provider you can help

by informing your patients about GARDIAN. By supporting and encouraging your patients and caregivers to register to GARDIAN and submit their data you will help to change the way we understand and treat nGD for the benefit of your patients and the nGD community.

As a patient/caregiver you can help

by registering for GARDIAN and submitting your valuable data. The process is easy and will not take too long.

gardianregistry.org

What is GARDIAN?

The Gaucher Registry for Development, Innovation & Analysis of Neuronopathic disease

A registry to improve disease understanding, management and support for patients with GD2 and GD3. Designed to study patients with GD2 and GD3 worldwide in a systematic and standardized manner.

A research platform to provide evidence-based data for advancing disease management, designing safer treatments and improving patient outcomes.

What are the benefits?

GARDIAN has the potential to significantly increase understanding of nGD and to improve standards of care for patients. The ultimate aims are to encourage the development of safer and more effective treatments leading to improved patient care and address caregiver burden. Equally importantly, GARDIAN will provide those affected by nGD with a much-needed public voice. It will help to communicate the reality of living with this ultra-rare and under-resourced disease and to allow patients and caregivers to become advocates for the nGD community.

Visit the GARDIAN website

info@gardianregistry.org