International Collaborative Gaucher Group (ICGG) Gaucher Disease Registry & Pregnancy Sub-registry

Status: RECRUITING

Eligibility Criteria

Sex: ALL
Age:
Healthy Volunteers: This study is NOT accepting healthy volunteers
Inclusion Criteria:

ICGG Gaucher Registry

- All patients with a confirmed diagnosis of Gaucher disease are eligible for inclusion in the Registry. Confirmed diagnosis is defined as a documented β-glucocerebrosidase deficiency and/or mutation in the β-glucocerebrosidase gene.
- For all patients, appropriate patient authorization will be obtained.

Gaucher Pregnancy Sub-registry:

- be enrolled in the ICGG Gaucher Registry.
- be pregnant, or have been pregnant with appropriate medical documentation available.
- provide a signed informed consent and authorization form(s) to participate in the Sub-Registry prior to any Sub-Registry-related data collection being performed.

Exclusion Criteria:

- No exclusion criteria for participation in the ICGG Gaucher Registry and Sub-registry.

Conditions & Interventions

Conditions:
Gaucher Disease, Cerebroside Lipidosis Syndrome, Glucocerebrosidase Deficiency Disease, Glucosylceramide Beta-Glucosidase Deficiency Disease
Keywords:
Gaucher Disease, Glucocerebrosidase Deficiency Disease

More Information

Description:
The ICGG Gaucher Registry is an ongoing, international multi-center, strictly observational program that tracks the routine clinical outcomes for patients with Gaucher disease, irrespective of treatment status. No experimental intervention is involved; patients in the Registry undergo clinical assessments and receive care as determined by the patient's treating physician. The objectives of the Registry are: * To enhance understanding of the variability, progression, identification, and natural history of Gaucher disease, with the ultimate goal of better guiding and assessing therapeutic intervention. * To assist the Gaucher medical community with the development of recommendations for monitoring patients, and to provide reports on patient outcomes, to optimize patient care. * To characterize the Gaucher disease population. * To evaluate the long-term effectiveness of imiglucerase and of eliglustat. Gaucher Pregnancy Sub-registry: The primary objective of this Sub-registry is to track pregnancy outcomes, including complications and infant growth, in all women with Gaucher disease during pregnancy, regardless of whether they receive disease-specific therapy. No experimental intervention is given; thus a patient will undergo clinical assessments and receive standard of care treatment as determined by the patient's physician.If a patient consents to this Sub-registry, information about the patient's medical and obstetric history, pregnancy, and birth will be collected, and, if a patient consents to data collection for her infant, data on infant growth through month 36 postpartum will be collected.

Contact(s): Laurie Bailey - laurie.bailey@cchmc.org
Principal Investigator:
Principal Investigator ID:
Phase:
IRB Number:
System ID: NCT00358943