



THE INTERNATIONAL GAUCHER ALLIANCE AND CERNER ENVIZA ENROLL FIRST PATIENT IN GARDIAN REGISTRY

April 26, 2022

KANSAS CITY, Mo., April 26, 2022 /PRNewswire/ -- [The International Gaucher Alliance](#) (IGA) and [Cerner Corporation](#) (NASDAQ: CERN) announce that the GARDIAN registry (Gaucher Registry for Development Innovation and Analysis of Neuronopathic Disease) is now open for registrations, and the first patient has already enrolled April 25, 2022. This registry, owned by the patient community, is led by the new [Cerner Enviza](#)SM operating unit that offers data-driven solutions and expertise that helps bring remarkable clarity to life sciences' and healthcare's most important decisions.



Gaucher Disease (GD) is an autosomal recessive disease and the most common Lysosomal Storage Disorder, with an incidence of about 1 in 100,000 live births. Three types exist: type I, the most common; type II and III also called neuronopathic GD (nGD). Today, GD has no cure; treatment options are available to address some aspects, but none are specific to the neurological impairments of nGD.

The GARDIAN registry will collect retrospective and prospective clinical and health outcome data for patients diagnosed with Type 2 and 3 Gaucher disease. Caregivers will provide their perspective for pediatric and some adult patients, as well as the impact of caring for a family member with nGD. Patients and caregivers will complete new patient and caregiver reported outcomes instruments, which are the basis of the first nGD specific instruments available.

"There remains huge unmet needs in care, support, understanding and effective treatments for the neurological manifestations of the disease. GARDIAN will play an important role into better understanding the impact of the disease on patients and caregivers and ultimately enabling improved quality of life and better patient outcomes," said Tanya Collin-Histed, CEO, International Gaucher Alliance.

Data collection will be made through Atom5TM [Aparito's](#) iOS & Android-compatible web and mobile app platform, which can capture eConsent, multiple, high-frequency data points from video, voice, wearables and electronic patient reported outcomes (ePROs). The Atom5TM global platform operates under ISO143485 QMS and ISO/IEC 27001 ISMS accreditations and is FDA CFR21 Part 11 compliant.

"We are excited to be part of this important patient-driven initiative, and that our Atom5TM platform will play a central part in generating insightful data which can support the whole community," said Dr. Elin Haf Davies, CEO, Aparito.

The GARDIAN registry aims to provide a more comprehensive understanding of the natural history of disease for nGD patients in order to accelerate early diagnosis and care for patients. Real-world evidence derived from GARDIAN will support compound development and inform the feasibility, protocol design and implementation of clinical trials.

"We are delighted to achieve this important milestone and look forward to seeing the GARDIAN registry grow," said Michael Fronstin, global head of clinical, Regulatory & Safety, Cerner Enviza. "Including patient and caregiver input will help future treatments be truly patient centric."

Cerner Enviza aims to accelerate the discovery, development and delivery of extraordinary insights and therapies to improve everyday health for all people globally. By combining decades of innovation, life sciences knowledge and collaborative research, *Cerner Enviza* provides data-driven solutions and expertise that helps bring remarkable clarity to life sciences' and healthcare's most important decisions. For more information, visit www.cernerenviza.com.

ABOUT THE INTERNATIONAL GAUCHER ALLIANCE (IGA)

The IGA is an international umbrella group representing the interest of Gaucher patients and those of non-for-profit Gaucher patient groups as well as rare disease groups throughout the world. While the IGA has an office in England, the IGA has almost 60 member associations around the globe. The IGA is a registered charity. The Gardian registry will be under the control of International Gardian Limited (IGL) a wholly owned subsidiary of the IGA

ABOUT CERNER

[Cerner's](#) health technologies connect people and information systems at thousands of contracted provider facilities worldwide dedicated to creating smarter and better care for individuals and communities. Recognized globally for innovation, Cerner assists clinicians in making care decisions and assists organizations in managing the health of their populations. The company also offers a connected clinical and financial ecosystem to help manage day-to-day revenue functions, as well as a wide range of services to support clinical, financial and operational needs, focused on people. For more information, visit Cerner.com, [Cerner Perspectives](#), connect on [Facebook](#), [Instagram](#), [LinkedIn](#), [Twitter](#) or join the discussion on Cerner's podcast [Perspectives on Health & Tech](#). Nasdaq: CERN.

ABOUT APARITO

[Aparito](#) is a global health tech company that brings clinical trials to patients and unlocks real-world data through mobile apps, video assessments and wearable devices. We provide innovative patient-centric solutions that integrate required clinical and regulatory expertise to capture patient data and develop digital endpoints for hybrid and decentralised clinical trials.

 View original content to download multimedia: <https://www.prnewswire.com/news-releases/the-international-gaucher-alliance-and-cerner-enviza-enroll-first-patient-in-gardian-registry-301533140.html>

SOURCE Cerner Corp.

IGA : Harry Albright harry@gaucheralliance.org; Cerner: Stephanie Greenwood, stephanie.greenwood@cerner.com; Aparito : Alexander Guest alexander.guest@aparito.com or info@aparito.com