March 2023 Newsletter

Our 2022 Impact Report is now available

The past 12 months have been a year of accomplishments for the IGA, and we are pleased to announce the release of our 2022 Impact Report. Download it to read how the IGA's work has impacted the global Patient Community in 2022, thanks to our volunteers, staff team and collaborators.

Download the Impact Report

GAUCHERALLIANCE.ORG/GO-WITH-GAUCHER

GO WITH GAUCHER 2023 GATHERING

VOLUNTEER NEEDED

The IGA is planning to hold a Go With Gaucher conference this year to provide young adult Gaucher patients with a supportive and educational environment to learn more about their disease, connect with others who have similar experiences, and engage in activities that promote personal growth and development.

We are looking for a volunteer to join the planning working group.

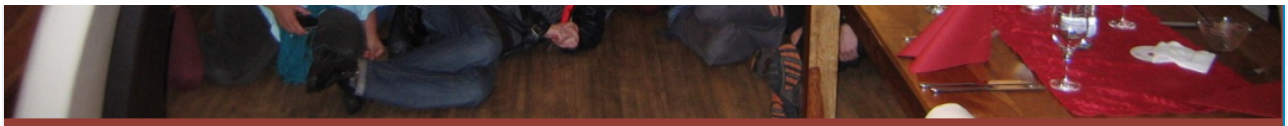
- Are you passionate about helping others and interested in rare genetic diseases?
- Do you want to build your organizational and communication skills?
- Do you enjoy working collaboratively with a team?
- Do you have a desire to help young people develop their leadership skills?

If so, this could be the opportunity for you!

Benefits include the opportunity to attend the international conference in-person, to gain experience in event planning and project management, and the satisfaction of knowing that you are making a positive impact in the lives of young adult Gaucher patients and their families.

For more information and a volunteer description, please contact Vesna:

vesna@gaucheralliance.org



Volunteer Spotlight

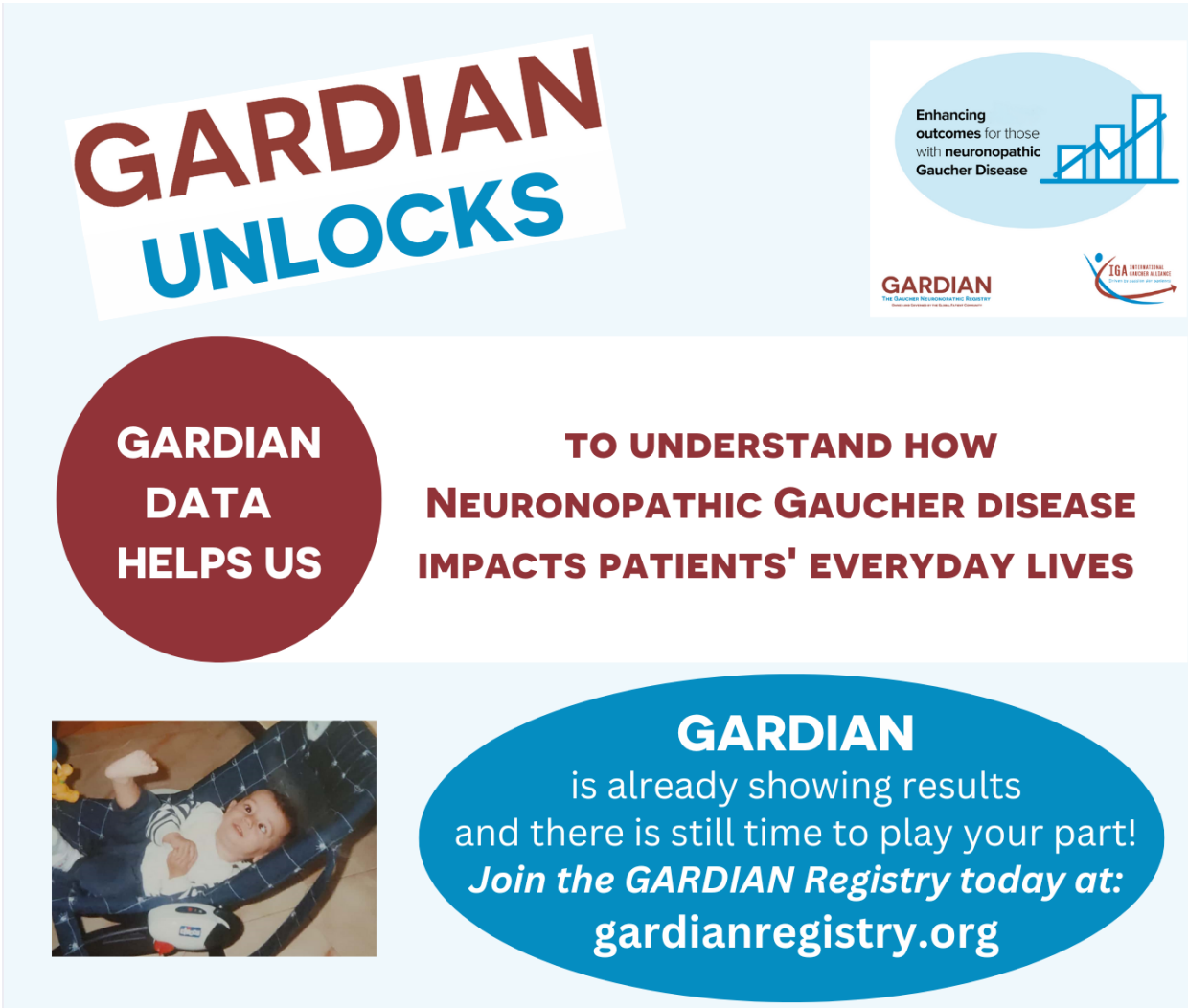
Andre Balzekiene

New Regional Manager
European region 2

Andre Balzekiene (Lithuania) will always remember the day she discovered her son was born with Gaucher‘s disease, neuronopathic type. This has changed Andre‘s life forever. The early accurate diagnosis helped to get the treatment as soon as possible and her son can live a life a good happy life, therefore she understands the importance of awareness of this rare disease. Andre emphasizes the importance of organisations like International Gaucher Alliance and social media platforms: “I truly want to contribute to this community by being the regional manager and spreading the message about Gaucher‘s so people would be diagnosed as soon as possible and patients together with the caregivers wouldn‘t feel left alone.“

Area of responsibility: European region 2 (Cyprus, Iceland, Kosovo, Liechtenstein, Montenegro, Malta, and Monaco)

Please contact Vesna if you are interested in volunteering with us.



Click here for more information and to register

IGA facilitates Central American webinar

On March 9th 2023, the Central American Parliament, PARLACEN, organized a webinar about the rare diseases situation in the Central American Integration System (SICA) Region.

This activity is part of the Parliament Health Commission plan that is working on the legal framework for rare diseases and reference centers in the region.

This activity was organized by the Commission, the Health Commission of the Science and Technology Council of Guatemala, the Ministry of Health of Dominican Republic, the Organization for Women in Science for the Developing World (OWSD), the IGA, Rare Diseases International and the Asociación Nacional Guatemalteca para las enfermedades de depósito lisosomal (ANGEL), and was sponsored by the European Parliament.

Participants were greeted by the Vice President of the Parlacen, Honorable Iliana Calles, MEP Tily Metz, Head of the Health Commission of the European Parliament, the President of the PARLACEN Health Commission, Hon. Carlos Sanchez MD, the President of the Guatemala Health Commission, Dr. Luis Castillo MD and the Chair of the OWSD, Dr. Nancy Sandoval, MD.

The webinar was facilitated by IGA Regional Manager and Presidente of ANGEL, Dr. Patricia Lucki, Ph.D.

The event had three speakers, Dr. José Elías García, Vice President of Latin American Genetics Association, who talked about Metabolic diseases and Gaucher Disease in the region, M.Sc. Paulina Peña, Member of IGA Board, talking about Women and rare diseases and, finally, Alejandra Sierra M. Sc., Director of the Genetic Lab of University Mariano Galvez, exposed the situation of genetic diagnostics in Guatemala.

The different organizations allied in this program are working with the Regional Health Ministers Committee on a Roadmap to provide care and support for rare diseases patients, their families and communities.

View a recording of the webinar (in Spanish)

Med-Lysosomal
20-21 April 2023, London, UK

The 3rd International Conference on
Lysosomal Diseases

Bioevents
Sharing Biomed Knowledge

For further information please contact:
rosemarie@bioevents-congress.com

The 3rd International Conference on Lysosomal Diseases (Med-Lysosomal2023) will take place 20-21 April 2023 in London, UK. This conference will cover recent advances in the understanding, diagnosis and treatment of Lysosomal Storage Disorders (LSDs) at large, but with a particular focus on the main (relatively more-common) Lysosomal Diseases: Gaucher, Fabry, Pompe and the various forms of MPS.

Visit med-lysosomal.com/congress-agenda/ for more information, including how to register.

International Gaucher Alliance

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