IGA INTERNATIONAL GAUCHER ALLIANCE

Driven by passion for patients

International advocacy for Gaucher patients since 1994

December 2023 Newsletter

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OUR OFFICE IS NOW CLOSED UNTIL WEDNESDAY 3 JANUARY.
WE LOOK FORWARD TO CONTINUING TO SERVE YOU IN 2024, OUR 30TH ANNIVERSARY YEAR.

VISIT OUR WEBSITE FOR MORE INFORMATION AND TO REGISTER
GARDIAN
THE NEURONOPATHIC GAUCHER REGISTRY
OWNED AND GOVERNED BY THE GLOBAL PATIENT COMMUNITY
WWW.GARDIANREGISTRY.ORG

IGA INTERNATIONAL GAUCHER ALLIANCE
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CELEBRATING
30
YEARS
of patient
advocacy

The IGA will be celebrating 30 years of serving the international Gaucher community in 2024.

Founded in Trieste in October 1994 as the European Gaucher Alliance, the IGA has evolved to become the go-to international organisation for Gaucher patients and their families, offering support and advice, and lobbying the pharmaceutical industry and governments on their behalf.

The Gaucher world has changed beyond all recognition since then, and throughout next year we will be celebrating the many achievements of the IGA and the contributions it has made to achieve better patient outcomes. We have many events planned, and we will be

asking for your help by sharing your memories and how that IGA has supported you and patients in your country.

Keep an eye on our website in the new year for details.

Towards Diagnosing Rare Diseases

Referral Behavior of Physicians in Europe

The IGA recently participated in a study led by Cerner Enviza to investigate the referral behavior of primary care physicians (PCPs) and specialists when encountering patients with undiagnosed symptoms.

The study concluded that:

• Differences in referral behavior exist among PCPs and specialists, within specialties, and across countries.

• PCPs are far less likely than specialists to suspect a rare disease when encountering symptoms they cannot diagnose.

• Specialists tend to refer patients after the initial visit more often than primary care physicians, when unable to diagnose a disease.

• Waiting for (or inconclusive) test results is the main reason for referral delay, followed by long waiting lists and preferring to watch and wait.

• Improved referral procedures could potentially benefit patient care by reducing time to diagnosis.

The study was presented as a poster at the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) meeting in November.

View the poster

Volunteer Spotlight

Carolina Toneloto

Carolina Toneloto mora no Brasil e foi diagnosticada com Doença de Gaucher tipo 1 aos 30 anos. É socióloga e professora, com tese de doutorado em saúde pública sobre narrativas da experiência da Doença de Gaucher em pacientes no Brasil.

Ela também é pianista e bailarina, e acredita fortemente no poder da troca de experiências e da educação em saúde para que a experiência com o adoecimento se torne mais fácil e leve.

Carolina Toneloto lives in Brazil, and was diagnosed with type 1 Gaucher Disease at the age of 30. She is a sociologist and professor, with a PhD in public health on narratives of the experience with Gaucher Disease in patients in Brazil.

She is also a pianist and ballerina, and strongly believes in the power of exchanging experiences and health education so that the experience of illness becomes easier and lighter.

Please contact us if you are interested in volunteering with the IGA..

Join us on Threads.

International Gaucher Alliance

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