



IGA

International Genetic Alliance

*to serve and voice the interests of families
involved in genetic and congenital conditions*

Worldwide network



Bringing together from continental/regional alliances:

vision, experience, expertise

partnerships,
positions on topics,
projects,
promotion,
publications,

commitment,
communication,
coordination,
collaboration,
capacity building,
conferences



IGA

is a meeting place for patient/parent organizations involved in chronic and debilitating diseases and with an interest in genetics and medical biotechnology.

is an alliance of continental and regional alliances of family organizations with an involvement in the opportunities and implications of genetics and biotechnology regarding its potential for prevention and treatment of serious diseases.

works for a world in which genetic diseases and acquired birth disorders are understood, prevented and cured and those affected supported.

aims at voicing the interests of patient organizations on the global level.

values collaboration with science, industry, financiers and policymakers in achieving its goals. You are welcome to join our efforts.

Vision

The International Genetic Alliance seeks a world where genetic conditions are understood, prevented, treated, ameliorated, and cured.

Mission

To promote medical genetic services, research, technologies, and access to information, in order to alleviate the burden of genetic conditions for individuals, families and communities.

Guiding Principles

- Genetic conditions affect individuals, families, and communities.
- All individuals, regardless of their genetic condition, culture, race, ethnicity, beliefs and/or socio-economic status, deserve equal rights and opportunities, without prejudice, discrimination or stigma.
- Relevant social, ethical and legal protections are critical to the progress and translation of basic science to services.
- Worldwide information sharing and resource exchange, with respect for diversity, increases capacity and decreases disparities.
- Meaningful global progress in policy, health care and research requires a patient/parent network in partnership with health professionals, industry and policy makers.
- Applications of education, medical genetic services, research, and biotechnology alleviate the burden of genetic conditions.

Aims and Objectives

- Support and accelerate research to prevent, treat, ameliorate and cure genetic conditions, through the translation of biotechnologies to accessible services.
- Develop policy in partnership with policy makers.
- Engage in partnerships with clinicians, researchers, industry, and NGOs with a shared mission.
- Establish best practice in medical genetic services that respect the autonomy of the individual, family, and community within a cultural context.
- Ensure access to relevant information, services, technologies, and medical treatments.

Board

Dianne Petrie	Australia	Association of Genetic Support Groups of Australasia (AGSA)
Alastair Kent	United Kingdom	Genetic Interest Group (GIG)/ European Genetic Alliances' Network (EGAN)
Ysbrand Poortman	The Netherlands	Dutch Genetic Alliance (VSOP)/EGAN
Sharon Terry	USA & Canada	Genetic Alliance (GA)
Ihor Bariliak	Ukraine	Ukrainian Alliance for Prevention of Birth Defects
Michael Livingston	United Kingdom	HEART EU, Patient Network
John Forman	New Zealand	New Zealand Organisation for Genetic Disorders
Darius Farhud	Iran	Iranian Alliance of Parent/Patient Organisations
Jai Rup Singh	India	Indian Alliance of Parent/Patient Organisations
Arnold Christianson	South Africa	Southern African Inherited Disorders Association
Martha Carvalho	Brazil	Brazilian Genetic Alliance
Brian O Mahony	Ireland	World Hemophilia Federation
Irma Nippert	Germany	World Alliance Organizations for Prevention & Treatment of Genetic & Congenital Conditions

IGA Members

North America
Latin America



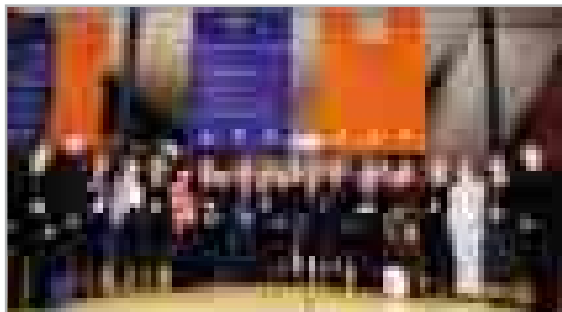
Asia
Australia
New Zealand
Europe
Ukraine
Southern Africa
Middle East



Liaison and Partners

IGA collaborates with various global organizations. It is IGA's strong conviction that only through adequate collaboration the goals of the Alliance can be achieved. IGA welcomes proposals for collaboration from other organizations on the international and continental with similar or adjacent objectives and activities.

- **WAO:** World Alliance of Organisations for Prevention and Treatment of Genetic and Congenital Conditions (www.world-alliance.org)
- **BioVision:** World Life Sciences Forum (www.biovision.org)
- **IFHGS:** International Federation of Human Genetic Societies (www.ifhgs.org)



Founding meeting, France, Lyon, April 2003

Central Secretariat



IGA

International Genetic Alliance

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