

DECLARATION

On Genetic & Congenital Disorders

New Delhi, 4 - 7 October 2009



Patient and Parent Organisations have been formed around the world. Initially they were a vehicle for mutual support of and by those affected by or at risk from serious, often life limiting genetic and congenital disorders.

In coming together, Patient and Parent Organisations have emerged as a force for change. Working in the interests of their members they have become a catalyst for spreading excellence e.g. in areas of research and health services. Their role has expanded from the provision of peer to peer support to encompass the stimulation and facilitation of research and development, the development of family-friendly health and social care services and awareness raising amongst the wider public. Increasingly, patient and parent organisations have a role to play in the formulation and implementation of policy at local, regional, national and international levels.

Patient and Parent Organisations have no wish to usurp the legitimate roles of doctors, scientists, industry, policy makers or other stakeholder interests. They do, however, expect and demand to be able to have their voice heard in decision making processes, the consequences of which will have an impact on the quality and possibly the quantity of their lives in a uniquely direct way.

The International Genetic Alliance (IGA), as a representative of patients and families living with genetic disease throughout the world, therefore calls on the political and policy community in all jurisdictions to adopt and act on the following eight principles:

- * Recognise and endorse the legitimate right of patients, families and the organisations that represent them to have their united voice heard in matters of policy-making and practice relating to the undertaking of research and the development and provision of health and other services and support.
- * Facilitate, directly and through the provision of financial and other support, the creation of Patient and Parent Organisations able to fulfil this strategic advocacy role.
- * Encourage and enable Patient and Parent Organisations to play an integrated part in the training of professional development of doctors and other health and social care professionals.
- * Acknowledge that, in many cultures and countries the impact of a genetic diseases in the family falls particularly heavily on women through the provision of care to affected family members, and target special assistance to carers in this position to support them in their caring role.
- * Prioritize the allocation of available resources to provide services that respond to the real needs of patient and families with genetic and congenital disorders in ways they feel to be most appropriate.
- * Respect the emotional and psychological impact of genetic disease on those affected, on parents and other family members especially siblings and develop expert counselling and other psychological support to meet this need.
- * Realise that new knowledge arising from research and development is changing the outcome for growing numbers of patients with genetic diseases and this will require flexibility in service provision and the opening up of new possibilities for those who benefit from these developments to lead long and fulfilling lives alongside their fellow citizens in society.
- * Commit to a sustained programme of investment in high quality biomedical research at development so that genetic diseases become more and more preventable, treatable and eventually curable.

This declaration is endorsed on the occasion of the 4th International Conference on Birth Defects and Disabilities in the Developing World, New Delhi, India 4th-7th October 2009 by:-

Dianne Petrie, Sydney, Australia

Acting President: International Genetic Alliance (IGA)
Executive Director: Association of Genetic Support of Australasia (AGSA)



Alastair Kent, London, United Kingdom

President: European Genetic Alliances' Network (EGAN)
Executive Director: Genetic Interest Groups in the UK (GIG)



Martha Carvalho, São Paulo, Brazil

President: Brazilian Genetic Alliance (BGA)



Jo-Anne Richards, Johannesburg, South Africa

Executive Director: Southern African Inherited Disorders Association (SAIDA)



Allan Bretag, Adelaide, Australia

President: World Alliance Neuromuscular Disorder Associations (WANDA)



Sanjana Goyal, New Delhi, India

President: Indian Association of Muscular Dystrophy (IAMD)



Changqing Zhu, Shanghai, China

Executive Director: Muscular Dystrophy Association China (MDA China)



Maryze Schoneveld van der Linde, Baarn, The Netherlands

On behalf of President International Pompe Association (IPA)



Irma Nippert, Münster, Germany

President: World Alliance of Organizations for the prevention and treatment of genetic and congenital conditions (WAO)



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