

*“seeks a world where genetic conditions are understood, prevented, treated, ameliorated, and cured”*

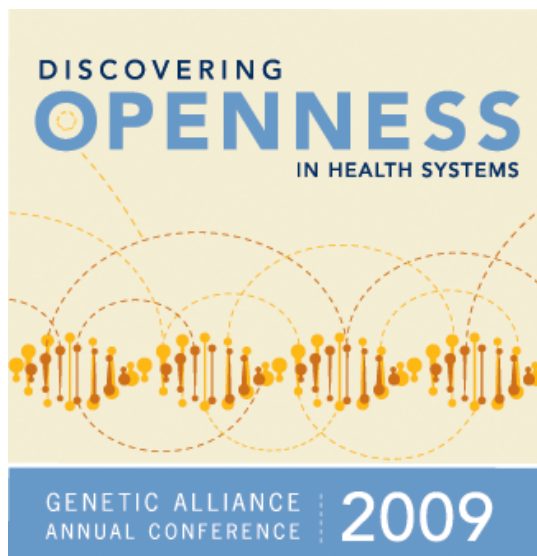
## Q4

### INTRODUCTION

This is already the last newsletter of 2008. It will inform you about events, progress in member countries, publications and projects. It serves to provide information and to facilitate communication and also to encourage emerging alliances. Your contributions for the first Newsletter of 2009 are welcomed at the 25<sup>th</sup> of February.

### UPCOMING EVENTS

**Discovering Openness in Health Systems**  
- the annual conference of Genetic Alliance – Washington DC., USA, 17 – 19 July 2009.



Genetic Alliance believes that an environment of openness is essential to the health of all individuals, families, and communities. The Genetic Alliance 2009 Annual Conference is a celebration of openness and an invitation to the community at large to abandon turf so that we can achieve truly productive transformation, of the health system and health itself.

*Discovering Openness in Health Systems* will bring together a diverse mix of advocates, health professionals, policymakers, industry professionals, and community leaders. Participants from all

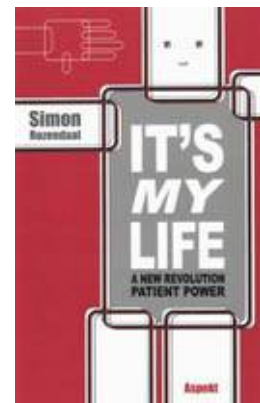
fields will engage in open discussion and debate on a range of relevant topics in genetics and advocacy. Over the course of three days, symposia, workshops, and panel discussions will focus on what ultimately matters: health. For more information please visit:

<http://www.geneticalliance.org/conference09>

### PROJECTS

#### **IT'S MY LIFE**

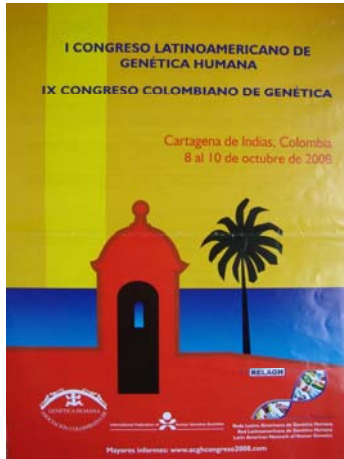
The book 'It's My Life' portrays a revolution that is taking place now! Twelve patients with a rare hereditary disorder all over the world have been interviewed. Their stories show a determination to take charge, to make a real difference. They want to get involved in the process of decision making. About medicines and treatments. It's their body, it's their life. These people embody a new energy a new promise to change medical science, the pharmaceutical industry and health care. We much welcome your assistance and support to advertise for this special book and to inspire other patients and patient organisations. This book can be ordered at any local bookstore. Copies ordered via the **European Genetics Alliances' Network** (EGAN) will bring a donation for each copy towards patient support activities. Your order can be send to [egan@egan.eu](mailto:egan@egan.eu)



The price for each book will be €15 (± US \$ 20) excluding shipping costs.

### PUBLICATIONS AND REPORTS

**I CLAGH I Congreso Latinoamericano de Genética Humana** (I Latin American Conference on Human Genetics), Cartagena de Indias, Colombia, 7 – 10 October, 2008.



The aim of the I CLAGH was to provide an overview of Medical Genetics and Public Health in Latin America, to promote communication among representatives from Latin American countries and to encourage their integration into a wider genetic network. The meeting was enriched by the participation of speakers from the EuroGentest Project who shared their experiences and insights into a variety of aspects of genetic testing, from essential knowledge in Medical Genetics for health professionals and quality assessment of genetic services to the importance of information for patients.



From left to right: Alejandro Giraldo (I CLAGH President), Martha Carvalho (Brazilian Genetic Alliance), Carlos Parga Lozado (Colombia), Sarah Berwouts (EuroGentest).

It was the first Brazilian Genetic Alliance (BGA) participation in Latin American level. The BGA attended the conference as the sole advocacy organization in the meeting. Participation of parents and patients organizations was strongly recommended during the presentations. It is time to prepare

the ground for the development of an effective networking.

## INSIDE INFORMATION FROM MEMBERS

### Genetics in Healthcare system in Brazil

The Brazilian Society of Medical Genetics (BSMG), in conjunction with the Brazilian Genetic Alliance (BGA), succeeded in spreading the word about the existence of the Public Policy and Clinical Genetics (PPCG) proposal which was elaborated 4 years ago and that had been stuck in the Ministry of Health since then (see IGA Newsletter Q3).

In raising the issue, BSMG and BGA drew the attention of the community, activists, politicians and government officials, and doing so outcomes were improved.

On December 5, 2008, the PPCG was finally approved and it is expected that in 2009 it is implemented, providing genetic services



Announcement in a Brazilian newsmagazine that Genetic Services will be provided via SUS.

through the SUS – Sistema Único de Saúde (Unified Health System), the public healthcare system in Brazil. This is an impressive achievement, since 85% of the population in Brazil is totally dependent upon SUS.

By: Martha Carvalho, Brazilian Genetic Alliance, [www.abg.org.br](http://www.abg.org.br)  
Email: [abg@abg.org.br](mailto:abg@abg.org.br)

### Genetic Alliance CEO Contributes to Disruptive Women in Health Care Blog



Sharon Terry, President and CEO of Genetic Alliance, has become a syndicated contributor to the **Disruptive Women in Health Care blog**. Amplified Public Affairs, a firm that helps develop and manage successful campaigns, strategic alliances

and online communications strategies, launched the platform in September 2008 as a space for provocative ideas, thoughts, and solutions in the health sphere. Although the focus of the blog is on encouraging the voices of women, men are welcome to share their thoughts as well. Thus far, Sharon has written posts about innovation, dissolving boundaries, the impact of the election for previously marginalized health conditions, and the spectrum of healthcare. There are over 20 disruptive women in health care contributing to the blog. To read the posts, visit <http://www.disruptivewomen.net>

## NEWS

### **NZORD: Mandatory fortification of bread with iodised salt – an important public health step for disease prevention**

Iodine deficiency is the world's most prevalent, yet easily preventable, cause of brain damage. Iodine deficiency disorders (IDD) can start before birth and jeopardizes children's mental health and often their survival. Serious iodine deficiency during pregnancy can result in stillbirth, spontaneous abortion and congenital abnormalities such as cretinism, a severe, irreversible form of mental retardation. In older children and adults it can result in Goiter, Impaired mental function, Hypothyroidism etc. To prevent these severe defects iodized salt has proved to be a cheap (US\$ 0.05 per person per year) solution. Alliances with UNICEF, ICCIDD (International Council for Control of Iodine Deficiency Disorders), international and bilateral agencies and salt industry have helped countries to set up permanent national salt iodization programmes where iodine deficiency is a public health problem. UNICEF estimates that globally 66% of households now have access to iodized salt.



*Iodizing table salt is one of the best and least expensive methods of preventing IDD. (photo source UNICEF/HQ97-0293/Noorani)*

Some regions in the world are naturally deprived of iodine in their soil. This arises through glaciation in the past, compounded by the leaching effects of snow, water and heavy rainfall, which removes iodine from the soil. Mountainous regions in Europe, China, India, South America, the lesser ranges of Africa and flooded river valleys all are iodine deficient. New Zealand also has a low level of iodine in their soil. To address the growing problem of iodine deficiency in New Zealand, Food Standards Australia New Zealand has decided to make it mandatory for bread manufacturers to replace non-iodised salts in breads with iodised salt. A Total Diet Survey (2003/04) estimated that the iodine intake of New Zealanders is only 57% of the recommended dietary intake. Reasons why the iodine intake of people has dropped are: a naturally low level of iodine in soil; reduction of the use of iodised salt as sea and rock salts have become more popular; general reduction of salt consumption and the move away from iodine based disinfectants in industry and home. Even when people do eat a balanced diet it can be difficult to get enough iodine in New Zealand, as vegetables, fruit and grains grown domestically have very low levels of iodine compared to other regions of the world. By choosing foods that are naturally high in iodine like seafood (fish, shellfish, seaweed), milk and milk products, seameal custard and eggs, people can ensure a higher intake of iodine. The New Zealand Ministry of Health recommends limiting overall salt intake to reduce the risk of stroke and heart disease, however, it advises that if salt is used for cooking and at the table it should be iodised. From: The Newsletter of NZORD written by John Forman, Executive Director.

## BECOME A MEMBER OF

**The international multidisciplinary community genetics network.** It's aim is to facilitate communication between all those working in the field of community genetics (and genomics). To become a member you only need to send an e-mail mentioning this desire to [commgennet@gmail.com](mailto:commgennet@gmail.com) As a member you are invited to stimulate your colleagues to become a member, or to send me the e-mail address(es) of (the) person(s) you propose.

**The Genetic Alliance Network.** Genetic Alliance offers a wide array of programs, resources, and events for all the individuals and organizations in our network, including:

- Annual Conference
- Genetic Alliance Webinars
- MemberForum
- Discussion listserv
- Weekly Bulletin, Policy Bulletin, and quarterly newsletter
- WikiAdvocacy and WikiGenetics
- Disease InfoSearch

To join the network, please visit:  
<http://www.geneticalliance.org/join>

**International Alliance of Patients' Organisations (IAPO)** is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred health care around the world. If you like to receive IAPO's newsletter, please go to this website: <http://www.patientsorganizations.org/index.pl?n=210;section=3> to submit your request

## RELEVANT WEBSITES

### ORGANISATIONS

**BIO** – a biotechnology industry organisation whose members are involved in research and development of innovative healthcare  
Website: [www.bio.org/healthcare/issues/](http://www.bio.org/healthcare/issues/)

**EGAN** – focuses on genetics, genomics and medical biotechnology and their implications.  
Website: [www.egan.eu](http://www.egan.eu)

**International Alliance Patient Organizations (IAPO)** - global alliance representing patients worldwide across all disease areas  
Website: [www.patientsorganizations.org](http://www.patientsorganizations.org)

**International Genetic Alliance (IGA)**  
Website: [www.internationalgeneticalliance.org](http://www.internationalgeneticalliance.org)

**March of Dimes** – is an organisation for pregnancy and baby health  
Website: [www.marchofdimes.com](http://www.marchofdimes.com)

**UNESCO** – gives information on life sciences and the implications on all species.  
Website: [www.unesco.org/shs/bioethics](http://www.unesco.org/shs/bioethics)

**WAO** – for the prevention and treatment of genetic and congenital conditions.  
Website: [www.world-alliance.org](http://www.world-alliance.org) (*under reconstruction*)

**WHO** – its Genomic Resource Centre provides information and raises awareness on human genetics and human genomics.  
Website: [www.who.int/genomics/en](http://www.who.int/genomics/en)

## MAJOR PROJECTS with International dimension and genetic alliances' engagement:

**CAPABILITY** – Capacity Building for the Transfer of Genetic Knowledge into Practice and Prevention  
Website: [www.capabilitynet.eu](http://www.capabilitynet.eu)

**PATIENTPARTNER** – to promote the role of organisations in the clinical trials context.  
Website: [www.patientpartner-europe.eu](http://www.patientpartner-europe.eu)

**EuroGenGuide** – contains information about genetic testing, counseling and research across Europe.  
Website: [www.eurogenguide.eu](http://www.eurogenguide.eu)

**EuroGenTest** – harmonizing genetic testing across Europe.  
Website: [www.eurogentest.org](http://www.eurogentest.org)

**Human Genome Project Information** – informs about project facts, education, medicine and the new genetics.  
Website: [www.genomics.energy.gov](http://www.genomics.energy.gov)

### RARE DISORDERS:

**Orphanet** – the portal for rare diseases and orphan drugs  
Website: [www.orpha.net](http://www.orpha.net)

**International Birth Defects Information Systems (IBIS)** – to promote better care and prevention of birth defects through information sharing  
Website: [www.ibis-birthdefects.org](http://www.ibis-birthdefects.org)

### IGA MEMBERS:

**Europe:** European Genetic Alliances' Network (EGAN), Website: [www.egan.eu](http://www.egan.eu)

**Central & Eastern Europe:** Central & Eastern European Genetic Network (CEE GN), Website: [www.ceegn.org](http://www.ceegn.org)

**Asia:** Indian Genetic Society

**Africa:** Southern African Inherited Disorders Association (SAIDA), Website: [www.saida.org](http://www.saida.org)

**Latin America:** Brazilian Genetic Alliance, Website: [www.abg.org.br](http://www.abg.org.br)

**North America & International:** Genetic Alliance, Website: [www.geneticalliance.org](http://www.geneticalliance.org)

**Middle East:** Iranian Genetic Alliance of Parent/Patient Organisations & Gulf State Alliance

**Australia and New Zealand:** Association of Genetic Support of Australasia (AGSA), Website: [www.agsa-geneticsupport.org.au](http://www.agsa-geneticsupport.org.au) & New Zealand Organisation for Rare Disorders (NZORD), Website: [www.nzord.org.nz](http://www.nzord.org.nz)

**UPCOMING INTERNATIONAL EVENTS  
with IGA - involvement and partnering**

**25 – 29 January 2008, Prague, Czech Republic**

Meetings of the European Forum for Good Clinical Practice; Central & Eastern European Genetic Network; European Genetic Alliances Network; Patients Roadmap to Treatment

**8 – 11 March 2009, Lyon, France**

BioVision 2009, Life Sciences as a Vector for Change and Sustainability

**17 – 19 July 2009, Washington DC, USA**

Discovering Openness in Health Systems - the annual conference of Genetic Alliance

**4 – 7 October 2009, New Delhi, India**

4<sup>th</sup> International Congress Birth Defects & Disabilities in a Developing World (ICBDD – DW)

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