International Genetic Alliance

"seeks a world where genetic conditions are understood, prevented, treated, ameliorated, and cured"

2009

For members and interested parties

 # 4

INTRODUCTION

This newsletter 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 next Newsletter are welcomed but not later than the 25th of February.

UPCOMING EVENTS

Global Approaches for Rare Diseases and Orphan Products - The 5th International Conference on Rare Diseases and Orphan Drugs in Rome (ICORD 2009), Rome, Italy, 23 – 25 February 2009.

ICORD

ICORD is an International Society for all individuals active in rare diseases and/or orphan drugs, including healthcare, research, academic, industry, patient organizations, regulatory authorities, health authorities, and public policy professionals. For the programme please visit:: http://www.icord.se/rome_2009.php

BioVision World Life Sciences Forum, Lyon, France, 8 – 11 March 2009.

bioVision

Since 1999 BioVision has organised a bi-annual, prestigious, international congress that attracts thousands of dedicated sages from all over the globe. Noble Prize Laureates, presidents, deans of academia, government policymakers and NGO delegates gather for this unique occasion to discuss the utilitarian side of the global agenda. IGA is contributing to this congress by organising sessions and routinely has it's bi-annual assembly in conjunction with this event in Lyon. For further information on BioVision visit: www.biovision.org

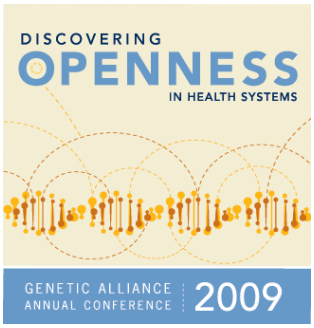
IGA board on the roof of the congress centre in Lyon.

At the conference the IGA organises a dinner debate on 'Human Rights and Citizenship in the age of genetics'. Speakers are Ysbrand Poortman (Secretary General IGA), Alastair Kent (President of EGAN) and Prof. Irmgard Nippert (President of the World Alliance Organizations for Prevention and Treatment of Genetic Disease). The theme deserves special attention because a gradual move seems to happen form patient to citizen. Genetics offer health opportunities to everybody; however this also includes rights and duties. Genetic Alliances bring together patients, families, consumers of healthcare and citizens. Some of the thematic issues to be addressed will be: - Human Rights and Citizenship are facing challenges and interrogations with genetics progress. – How to preserve humanity? – Protecting the citizen against the misuse of genetic information. – How citizens can best benefit from genetic progress. – Educating and informing citizens about genetics to enable them to manage their interests.
www.biovision.org/2009-debate-dinners.html

6th International Meeting of the International Society for Neonatal Screening, Prague, Czech Republic, 26 – 28 April 2009.

On April the 26th at 20.00 hrs a workshop of ISNS and EGAN/Eurordis and support groups will be held on the subject 'Consensus building on neonatal screening'. Please look for more information at: www.guarant.cz/isns/Text/welcome

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 territory* so that we can achieve a 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

4th International Conference on Birth Defects and Disabilities in Developing Countries, India, New Delhi, 4 – 7 October 2009.
"Translating Research into Care and Prevention."

The theme of the conference is 'Establishing effective services for the treatment/handling and prevention of birth defects'. Earlier conferences took place in Johannesburg, Beijing and Rio de Janeiro. IGA is a partner in the organisation of this bi-annual international congress on Birth Defects and Disabilities in a Developing World. The conference is unique because it will bring together various stakeholders such as health professionals, social workers,

patient/parent organisations, young volunteers, administrators, policy makers and the public health community. It will cover many aspects such as surveillance programmes and registries; major risk and preventive factors; individual and community-level prevention and strategies, including micronutrient fortification and immunization programmes and preconception health and health care; counselling and care of common birth defects and genetic disorders; rehabilitation and rights of disabled and legal frameworks for their protection.
IGA is a partner in organising and promoting these conferences. Together with Thalassemics India (an exemplary patient/parent organisation in India, see: www.thalassemicsindia.org) IGA is organising a plenary session on 'The Important Role of Patient/Parent Organisations'. Patients and parents from India, Europe, Latin America and the Middle East will present from personal experience, table the situation and needs in their region and speak about their association's contribution to support the families and mention their efforts and results in improving the healthcare system. Parivaar, the Indian Alliance of associations involved in mental retardation will meet before the ICBDD-congress in New Dehli.

SUPPORT NEEDED

International Registry for Krabbe Disease
The Centre for Krabbe disease, the clinical arm of the Hunter James Kelly Research Institute, has developed an international registry for patients with Krabbe disease. We are trying to learn as much as possible about all forms of this rare, devastating condition. This has become especially crucial now that there is universal newborn screening for

Krabbe disease in New York State and soon in Illinois. We have found that neither the baby's level of enzyme nor the genetic mutation has been able to predict which baby will go on to develop the rapidly progressive early infantile form of the disease (which requires emergency consideration of bone marrow transplantation) versus the later childhood, adolescent or adult forms. Therefore we are collecting information on the first symptoms of the disease, enzyme activity, genetic mutations and the results of the diagnostic studies (MRI, spinal tap, nerve conduction velocities, etc) that were performed by your child's doctor.

If you consent to share your child's story with us, I will mail you a brief questionnaire as well as a release of medical information for your child's doctor. All identifying information will be removed prior to data analysis.

Can you help us? If you would like more information, please contact me (email, phone or letter) at the address listed below. Thank you!

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PUBLICATIONS AND REPORTS

From Latin America

I CLAGH I Congreso Latinoamericano de Genetica 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 at Latin American level. The BGA attended the conference as the sole advocacy organization in the meeting. Participation of parent's and patient's organizations was strongly recommended during the presentations. It is time to prepare the ground for the development of effective networking.

From Eastern & Central Europe

Patients' Roadmap to Treatment

The Central and Eastern European Genetic Alliance (CEEGN), started in 2003, obtained legal status in 2008 and organised a multi

The CEEGN meeting in Prague.

round-table conference in Prague at the end of January 2009 with the theme 'Patients' Roadmap to Treatment'. The conference contained an assembly, a boardmeeting, European Union project meetings on:

Eurogenguide www.eurogenguide.org.uk, lead by the British Genetic Interest Groups - GIG,
Patient Partner in Clinical Research www.patientpartner-europe.eu, led by the Dutch Genetic Alliance - VSOP,
EUmitocombat www.eumitocombat.org presented by the World Alliance Neuromuscular Disorder Associations - WANDA and
TREAT-NMD www.treat-nmd.eu, lead by the European Neuromuscular Centre - ENMC.

The conference was organised by CEEGN at the initiative of IGA in the context of it's programme to support the development of regional and national genetic networks. Co-organisers were WANDA (in collaboration with EAMDA), EFGCP/EGAN Working Party on Patients' Roadmap to Treatment. All projects have an international overhead. In the next newsletter we will return to this subject.

All participants of the CEEGN meeting in Prague.

The conference was attended by representatives from 15 Central and Eastern European countries (including Balkan countries and Turkey) and was funded by grants from the European Union and Genzyme.
The conference was followed by a congress of the European Forum Good Clinical Practice with a focus on "Research Integrity". It is a standard EFGCP-procedure to invite 5 patient representatives to give an input in EFGCP- conferences.

From Europe
Collaboration Roche and Genetic Alliances (EGAN & IGA)
The European Genetic Alliances' Network, also on behalf of IGA, and Roche have fruitful collaborations focussing on the contribution of patients and patient organisations to the research and drug development process. This is facilitated by the issue of publications containing answers on frequently asked questions on topics such as biobanks, clinical trials and glossaries on terms to make the research process more transparant for patients. Part of the programme is also the annual organisation of a strategic workshop to discuss issues that will influence science and health policy in the coming years. This time the workshop dealt with Health Technology Assessment and Personalised Medicine.

As a result of this collaboration these three publications (see picture above) are now available and can be downloaded from the IGA-website:
www.internationalgeneticalliance.org

INSIDE INFORMATION FROM MEMBERS

From Brazil
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

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

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 #3). 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 will be implemented, providing genetic services 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
Email: abg@abg.org.br

From United States

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

From New Zealand

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 brian 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 bi-lateral agencies and the 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)

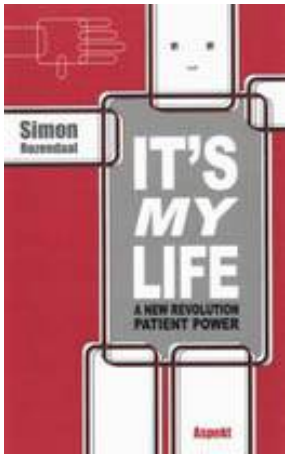
Some regions in the world are naturally deprived of iodine in their soil. This arises through glaciation in the past, compounded by the leaching effects of snow, water and heavy rainfall, which removes iodine from the soil. Mountainous regions in Europe, China, India, South America, the lesser ranges of Africa and flooded river valleys are all iodine deficient. New Zealand also has a low level of iodine in the 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 salt 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 (a traditional New Zealand dessert) 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.

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 welcome your assistance and support in advertising 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



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

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 As a member you are invited to stimulate your colleagues to become members 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 programmes, resources and events for all the individuals and organizations in our network, including:
1) Annual Conference, 2) Genetic Alliance Webinars, 3) MemberForum, 4) Discussion listserv, 5) Weekly Bulletin, Policy Bulletin, and quarterly newsletter, 6) WikiAdvocacy and WikiGenetics, 7) 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 would like to receive IAPO's newsletter, please visit 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/

EGAN – focuses on genetics, genomics and medical biotechnology and their implications.
Website: www.egan.eu

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

International Genetic Alliance (IGA)
Website:
www.internationalgeneticalliance.org

March of Dimes – is an organisation for pregnancy and infant health
Website: www.marchofdimes.com

UNESCO – gives information on life sciences and the implications on all species.
Website: www.unesco.org/shs/bioethics

WAO – for the prevention and treatment of genetic and congenital conditions.
Website: www.world-alliance.org

Genetic Interest Group (GIG) – is a national alliance of patient organisations of genetic disorders.
Website: www.gig.org.uk

Erfocentrum – Dutch national genetic resource and information centre.
Website: www.erfocentrum.nl/english.php

WHO – it's Genomic Resource Centre provides information and raises awareness on human genetics and human genomics.
Website: 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

PATIENTPARTNER – to promote the role of organisations in the clinical trials context.
Website: www.patientpartner-europe.eu

EuroGenGuide – contains information about genetic testing, counseling and research across Europe.
Website: www.eurogenguide.eu

EuroGenTest – harmonizing genetic testing across Europe.
Website: www.eurogentest.org

Human Genome Project Information – informs about project facts, education, medicine and the new genetics.
Website: www.genomics.energy.gov

RARE DISORDERS:

Orphanet – the portal for rare diseases and orphan drugs
Website: 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

IGA MEMBERS:

Europe: European Genetic Alliances' Network (EGAN), Website: www.egan.eu
Central & Eastern Europe: Central & Eastern European Genetic Network (CEE GN), Website: www.ceegn.org
Asia: Indian Genetic Society
Africa: Southern African Inherited Disorders Association (SAIDA), Website: www.saida.org
Latin America: Brazilian Genetic Alliance, Website: www.abg.org.br
North America & International: Genetic Alliance, Website: 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 & New Zealand Organisation for Rare Disorders (NZORD), Website: www.nzord.org.nz

UPCOMING INTERNATIONAL EVENTS with IGA - involvement and partnering

23 – 25 February 2009, Rome, Italy
International Conference on Rare Diseases and Orphan Drugs (ICORD 2009) – Global Approaches for Rare Diseases and Orphan Drugs

8 – 11 March 2009, Lyon, France
BioVision 2009, Life Sciences as a Vector for Change and Sustainability

26 – 28 April 2009, Prague, Czech Republic
The 6th International Society for Neonatal Screening (ISNS) Meeting - European Regional Meeting in Neonatal Screening

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

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