February 2008

For members and interested parties

International Genetic Alliance

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

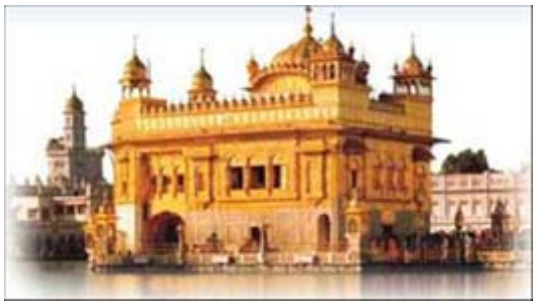
UPDATE

INTRODUCTION

Welcome to the first IGA newsletter in which we would like to inform you about what is happening in the world of genetics. We hope that in 2008 the IGA will further increase in importance and relevance for the numerous families involved in genetic and congenital conditions. This newsletter aims to update you and provide opportunities to react, to advise and to comment on the work that the IGA undertakes. We invite you to contribute and send your comments to the editor of this newsletter Maryze Schoneveld van der Linde of Patient Centered Solutions. She can be contacted at: maryze@pacesworld.com

UPCOMING EVENTS

"Omics in the 21st century" - 5th International Symposium on Genetics, Health and Disease, India, Amritsar, 17-19 February 2008.



The word 'Omics' in the title of this symposium refers to the several technologies like Genomics, Transciptomics, Proteomics and Metabolomics. These technologies will promote a powerful insight into the molecular mechanisms of genomics and diagnostics.
In the past we have focused on the raw data of genetic information. Now we intend to focus on the function of genes and their relationship and interaction with the natural environment. With these technologies the standard of health care will improve and provide for 'individualized' treatment. A holistic, system-wide approach to modern biology is the requisite for the molecular key questions of genetic function and interplay. You are invited to participate in this symposium for sharing knowledge, for interactions and to build collaborations the world over. You can download the brochure with all information from: http://www.gndu.ac.in/. You are kindly requested to add this brochure to your website, mention the symposium in your list of conferences & congresses and draw the attention of potential participants on this great event. The President of the Indian Genetic Alliance, Prof. Jai Rup Singh is the chair of the symposium. For more information see http://www.world-alliance.org and look at 'upcoming meeting'.

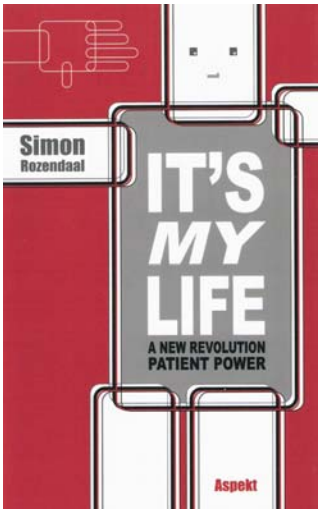
'Global Approaches for Rare Diseases Research and Orphan Products Development (ICORD)' –
The 4th International Conference on Rare Diseases and Orphan Drugs, USA, Washington DC, 20 – 22 May 2008.

The overall aim of the ICORD 2008 Meeting is to develop constructive International collaborations that will result in true advantages for patients with Rare Diseases. It will provide a forum for all stakeholders in rare diseases and orphan products. Everyone active in rare diseases and/or orphan drugs, including health care, research, academia, industry, regulatory authorities, health authorities and public policy professionals is invited for this conference.
For more information see http://www.icord.cc

PROJECT

IT'S MY LIFE
After an extensive preparation the book 'It's My Life' has been published in 2007. This book portrays a revolution that is taking place now! The Dutch science-writer Simon Rozendaal has interviewed twelve patients

with a rare hereditary disorder all over the world. Their stories show a determination to take charge, to make a real difference. They don't want to wait until someone else does something for them. They want to get involved in the process of decision making. About medicines, about their treatments, about their bodies, about their lives. It's their body, it's their life. These people all embody a new energy with the promise to change medical science, the pharmaceutical industry and health care: Patient Power, the heir to Womens Power, Black Power and Gay Power. The message of this book must be widely distributed. Patients all over the world must know that their voice and opinion will be heard when they really take the lead. Researchers, physicians and pharmaceutical industries must be encouraged by us.



Simon Rozendaal (right) signing one of his books together with Bea Schepper (middle) and Ysbrand Poortman (left)

We need 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, but we kindly request you to order it via the **European Genetics Alliances' Network** (EGAN)). For every copy ordered through EGAN a donation will be made 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.

PUBLICATIONS AND REPORTS

Many have participated in the 3rd International Congress on Birth Defects & Disabilities in a Developing World held in Rio de Janeiro. The organisers created a photo gallery on their website and you may like to read the Rio declaration at http://www.3rdconference.com.br

A well attended joint session Brazilian Genetic Alliance & International Genetic Alliance

INSIDE INFORMATION FROM MEMBERS

Fundación FOP in Argentina

Moira Liljesthrom

The "Fundación FOP, *to promote research and the improvement of persons with Fibrodisplasia Ossificans Progressiva*", is a non profit organisation, that is running a three year research project on rare genetic diseases, which was granted by the Secretary of Science and Technical Affairs of República Argentina. Moira Liljesthrom is the head of the project. She has a child with an extremely rare disease and knows very well some of the particular emerging issues. The project is designed to analysse the specific problems suffered by affected people and their families in different social and regional backgrounds. With a good analysis of these problems well based policies can be supported and the situation of affected people can be improved by providing valuable information and focusing the best means to empower them. This can be done through increasing their capabilities as an organisation, sharing of information and improved communication. This analysis will cover the medical, social and legal issues and the state of scientific investigation, comparing to more developed

countries. Based on the results of this analysis, the project will organise an information office to collect and offer helpful information and links to data on rare genetic diseases, as well as proposals for public policies for these people and their families. The project includes carrying out surveys and interviews with patients and physicians all over the country, in order to provide a robust base for the political proposals.

The survey will be performed among people affected by 12 selected rare genetic diseases. At the moment a list of people affected from one of the diseases is being made. Then a random sample will be drawn for the survey. Some of the selected diseases have patient organisations which are contacting their members (according with legal regulations on privacy) but others don't have a patient organisation so it's more difficult to find these patients. Because of this, Fundación FOP is taking information to many doctors and hospitals in Argentina. After approval of their Ethic Committees, many of them are collaborating with the project. The research project also achieved to get the formal support of the National Direction of Health for Mothers and Children, and from a Division of the Health Department of the City of Buenos Aires. http://www.fundacionfop.org.ar

Brazilian Genetic Alliance (BGA)

Step by step the Brazilian Genetic Alliance (http://www.abg.org.br) has consolidated its position as a leading voice in the genetic advocacy community. Significant progress has been made in promoting awareness about genetic conditions and in clarifying the role of an advocacy organisation. We had productive meetings on genetic issues, increased our membership with new parent and patient organisations and have extended our network. At the Genetic Alliance Annual Conference in Bethesda (USA) BGA presented the workshop *Widening Perspectives on Advocacy: From Visionary Leaders to a Coalition of Grassroots Organisations*.

In response to the National Agency of Supplementary Health consultation on updating medical procedures and minimum health insurance coverage, BGA presented a position paper on the importance of the health insurance coverage for the necessary procedures for the diagnosis of genetic diseases, including genetic counseling for people at risk of genetic diseases. BGA also gave lecture on patient organisations at a WHO Collaborating Centre for the Development of Nursing Research. A position paper has been presented in favour of the right of access to information about the quantity of phenylalanine in industrialised food during the meeting with representatives of Federal Public Ministry and of the National Agency of Sanitary Vigilance – ANVISA.

BGA took part in the launching of the booklet

"The disabled person's vote – more than a right, a path to dignity" that took place in São Paulo House of Representatives.

NEWS

Innovative Medicines Initiative (IMI)

The Council of the European Union formally approved the Regulation setting up the Innovative Medicines Initiative (IMI) on December 20 2007. The IMI is a unique partnership between the European Community and European Federation of Pharmaceutical Industries and Associations (EFPIA). It supports the faster discovery and development of better medicines for patients and to enhance Europe's competitiveness by ensuring that its biopharmaceutical sector remains a dynamic high-technology sector. The European Commission and EFPIA propose to create and operate a new Public Private Partnership, the IMI Joint Undertaking. The IMI Joint Undertaking will fund Patient Centred Projects. These IMI Patient Centred Projects will address the principle causes of delay in the current process of discovering and developing new medicines. These research projects will not develop new drugs per se but will generate new knowledge about diseases and new tools and technologies, thus, better underpinning, improving and accelerating development of new therapies. For more information see: http://www.imi-europe.org/

Join the IMCGN

The International Multi Disciplinary Community Genetic Network (IMCGN) aims at facilitating communication between all those working in the field of community genetics and genomics. Membership, without

costs but with the obligation of enlarging the network, includes receiving their newsletter. This newsletter updates you about relevant publications and meetings. Give it a try by sending a mail to commgennet@gmail.com with the request to be put on the mailing list. IMGCN is interested also in your publications and events as far as of importance for their members.

Central & Eastern European Genetic Network (CEEGN)

CEEGN is a patient-driven network organisation, consisting of patients, parents, individuals, and scientists (Scientific Advisory Board) from Central and Eastern European countries (CEEC).

CEEGN has a focus on the common needs of patients and their families related to the backward position of CEEC countries, and strives to facilitate their integration in the EU as a top priority. CEEGN aims on building up awareness and knowledge on common and rare genetic conditions among the public and scientists, increasing political influence in the arena of genetic disease, diagnosis and treatments, and promoting research in causes and cures for serious diseases in countries of Central and Eastern Europe. Ultimately, we encourage and support building up of local genetic patient umbrella organisations in the countries of CEEC where there are no such organisations existing, to serve as the main information resource to the patients, parents and families in Central and Eastern European countries, as well as to represent their voice in the EU.

CEEGN was founded in October 2003 in Cavtat, Croatia, and its registration is ongoing in The Hague, the Netherlands. Currently, we have members from Poland, Hungary, Turkey, Slovenia, Bulgaria, Romania, Bosnia, Russia, Serbia and Croatia.

CEEGN is a member of European Genetic Alliances' Network (EGAN), thus functions in line with EGAN and IGA (International Genetic Alliance). We welcome as well collaboration with all organisations, institutions and societies with similar goals.

CEEGN takes part in the EU projects "Eurogenguide" and "Eurogentest", where it aims to become the main channel for distribution of the outcomes to the patients and scientists in Central and Eastern European countries. CEEGN aims to increase its activities by partnering in various major EU/DG projects in 2008 and beyond, such as "Roadmap to treatment", "Patients participation in clinical research". CEEGN plans its annual meeting in conjunction with the European Society of Human Genetic conference (ESGH). http://www.ceegn.org

At the meeting in Basel on January 2008 with members from Bulgaria, Hungary, Poland and supportive representatives of the Netherlands and Germany.

UPCOMING EVENTS

17 – 19 February 2008 Amritsar, India
5th International Symposium on Genetics, Health and Disease

20 – 22 May 2008 Washington DC, USA
4th International Conference on Rare Diseases and Orphan Drugs

6 – 9 October 2008 Paris, France
EuropaBio and European Genetic Alliances' Network (EGAN)

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

November 2009 New Dehli, India
4th International Congress Birth Defects & Disabilities in a Developing World (ICBDD – DW)

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