

Many of the voluntary groups which support persons with rare disorders and their families were there as were their members.

This was part of a European-wide awareness campaign for rare conditions. Similar functions were held right across the EU and were coordinated by the European Organisation for Rare Diseases (EURORDIS) of which our organisation is an active member. EURORDIS represents 300 organisations in 34 countries, covering more than 1,000 rare disorders.

The European Parliament held a Public Hearing in Brussels on 4 March to present the issue of rare disorders as a public priority and to promote national plans for rare disorders in member states. At present, France is the only EU country to have a rare disorders plan in place.

We are most grateful to the Community Foundation for Ireland for their support and we know from the response we have since received that it has helped many people who may otherwise have felt isolated.

The Community Foundation provides a channel for organisations and individuals to undertake effective community based charity giving. It operates a small grant scheme and this year the priority was to assist projects working to respond to isolation and to develop a more diverse society.

For further information visit:

www.grdo.ie

www.eurordis.org

www.communityfoundation.ie



Michael James Ford and Fergus Linehan of the Theatrical Cavaliers Cricket Club presenting Judy Windle (GRDO Secretary) with fundraising proceeds.

Table Quiz Fundraiser

The Theatrical Cavaliers Cricket Club kindly designated GRDO as their chosen charity for their Annual Gala Charity Quiz on Sunday April 27th at 7.30pm in the teachers club Parnell Square.

The night was very entertaining and raised a marvellous €5,000.00 for GRDO. Special thanks to the committee of the Theatrical Cavaliers Cricket Club - in particular Michael James Ford, Stephen Swift, John Delaney and Fergus Linehan for organising the event.

We would also like to thank all those who donated prizes.



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GENETIC & RARE DISORDERS ORGANISATION

NEWSLETTER

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COMING UP IN THIS ISSUE:

- Launch of Information leaflet
- Funding Cuts affect Services
- Rare Disorders Day
- Fundraising

Welcome

Welcome readers, to the first edition of our new GRDO Newsletter. The Genetic and Rare Disorders Organisation (GRDO) is an Irish alliance of voluntary groups, involved with genetics and other rare disorders. We hope that this publication will provide you, our readers, with some useful information while updating you on some of the work we undertook this year.

Kindly supported by The National Lottery

www.grdo.ie



GRDO members and representatives supporting the first ever pan-European Rare Disorders Day at the Mansion House on 29th February, 2008.

GRDO Launches Information Leaflet

The Genetic and Rare Disorders Organisation (GRDO) is a non governmental organisation. GRDO acts as a national alliance for voluntary groups representing the views and concerns of people affected by or at risk of developing genetic or other rare disorders.

The Genetic and Inherited Disorders Organisation, trading as Genetic and Rare Disorders Organisation, is a company limited by guarantee and is registered as a charity and run by volunteers. The organisation took the decision to include *rare* in its title in order to reflect the groups and individuals we represent. A rare disorder is a disorder affecting less than 1 in 2000 people. It is estimated that there are 140,000 people in Ireland with a rare disorder. 80% of rare disorders are of genetic origin.

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Funding Cuts Affect the National Centre for Medical Genetics

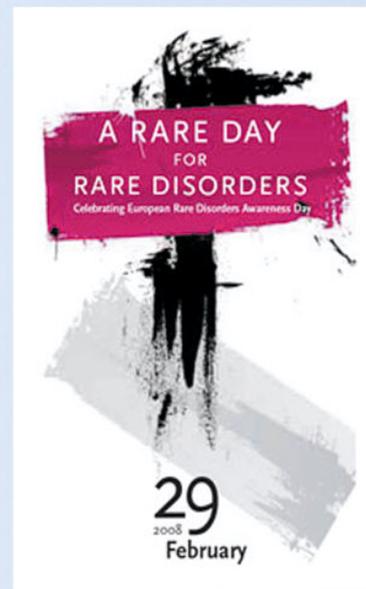
The National Centre for Medical Genetics (NCMG) was established at Our Lady's Hospital Crumlin in 1994. The NCMG aims to provide a comprehensive service for all patients and families in the Republic of Ireland affected by or at risk of a genetic disorder. The Centre provides a service for both children and adults. It is the only centre of excellence in Ireland which provides clinical and laboratory services for our members.

NCMG has recently informed service users and patients that they have been forced to reduce services due to chronic underfunding and the acute financial situation at Our Lady's Children's Hospital, Crumlin. NCMG was already under-resourced and there is a requirement for a number of additional posts and additional funding to enable it to carry out the workload it already has and which is increasing by the day. We are extremely alarmed to hear that there are to be further reductions in staff numbers which will inevitably lead to some vital services being curtailed. This will mean that people with genetic conditions will not have access to genetic tests or genetic counselling which, for some families, will be catastrophic.

A Rare Day for Rare Disorders

GRDO organised an information event in the Mansion House Dublin to celebrate the first European Awareness Day on 29th February. GRDO received a grant from the Community Foundation, which was part-funded by the Dr. Alison Byrne Fund and enabled us to organise our meeting to raise awareness of rare disorders in Ireland.

The meeting was addressed by Professor Andrew Green, Director of the National Centre for Medical Genetics (NCMG) in Crumlin who spoke about the work of NCMG and the need for greater awareness and support for genetic and rare conditions. Two people affected by a rare condition spoke about how their condition affects their lives.



Judy Windle of GRDO said "the low profile and public awareness of rare disorders in Ireland means that Irish people are facing tremendous difficulties. Scarcity of information and expertise and a lack of specific health policies translate into delayed diagnosis and difficulties in accessing care. Often people with rare conditions cannot find a relevant support network resulting in a feeling of vulnerability and isolation for them and their families". She added "When you look at the incentives in Europe and what is

happening in the different member states of the EU, you see almost nothing happening in Ireland. To-day we hope will show those affected that they are not alone and that there is someone who can help point them in the right direction."

"GRDO acts as a primary source of information and support for Irish people affected by rare disorders and an important part of the Awareness Day is to make such people aware that the support is available to them." she said.

GRDO was joined by the Medical Charities Research Board, by RehabCare the health and social care division of Rehab Group and by the Irish Platform for Patients, Science and Industry (IPPOSI). There was a large attendance at the meeting with representation from the universities and the medical fraternity as well as politicians and officials from the Health Service Executive.