

PRESS RELEASE: 28 February 2011

GRDO calls for establishment of National Rare Disease Office

Survey of patients highlights urgent need for development of co-ordinated healthcare pathways and a central information point on rare conditions

On the eve of international Rare Disease Day, the Genetic and Rare Disorders Organisation (GRDO) Ireland's national rare disease alliance, is calling for the urgent establishment of a National Rare Disease Office to address serious shortfalls in health and social care for the estimated 6% to 8% of the population affected by rare conditions.

Results of a survey of individuals with rare conditions, published by GRDO today, reveals significant difficulties in the areas of access to diagnosis, information and to treatment, as well as a lack of coordination in delivery of services. 13.3% of respondents report waiting more than 10 years for diagnosis and 37.2% report receiving an incorrect diagnosis before the correct one. 73.1% of those surveyed report attending more than one hospital consultant or other medical professional for treatment yet 44.8% report not having a specific point of contact to go to with questions about their condition. 62.5% of respondents list the Internet as their main source of information.

The establishment of a National Rare Disease Office in Ireland and the development of co-ordinated healthcare pathways are the two changes to the healthcare system that respondents would most like to see (82%), followed by more information about their conditions (73%).

A national office would act as a focal point for the development of a national registry of rare conditions, and a vitally needed information portal for patients and medical professionals. It would help patients to access Centres of Expertise, whether in Ireland or abroad, and ensure the best model of care for patients with faster diagnosis and access to treatment. It would also be cost efficient.

Speaking ahead of Rare Disease Day on 29 February, Chairperson of GRDO, Avril Daly, stressed that "the lack of a central co-ordinating point of information on rare conditions, and the lack of clearly defined healthcare pathways for those affected, puts this already marginalised group of people at even greater disadvantage. There are also hidden costs to the state associated with delayed diagnosis, inappropriate interventions and lack of co-ordinated care for people with rare conditions."

"What must be prioritised, without further delay, is the establishment of a clinically led National Rare Disease Office as part of the programme for clinical care. A business plan has been submitted to the HSE demonstrating that providing high quality services to rare disease patients in a cohesive way through a central office can be cost-effective and will lead to better management of services and, most importantly, better outcomes for patients and their families.

"Ireland is on track to develop a national rare disease plan by 2013, in keeping with the 2009 EU recommendation. There is great solidarity among the rare disease community globally and at national level. Patient representatives, medical professionals, researchers, and policy makers have been working hard together to develop a National Plan for Ireland, and we look forward to seeing the public consultation process taking place in April this year," Ms Daly continued.

For more information on the survey conducted by GRDO see www.grdo.ie.

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Notes to editors:

About Rare Disease

A rare disease affects fewer than 1 in 2000 people. There are more than 6000 rare diseases. Between 6% and 8% of the population are affected by a rare condition – that's 270,000 + people in Ireland alone.

Genetic and Rare Disorders Organisation (GRDO)

GRDO, the Genetic and Rare Disorders Organisation, is the national rare disease alliance in Ireland, working on behalf of individuals and voluntary groups, to provide a strong voice and achieve better services for all those affected by rare conditions.

Rare Disease Day 2012

To mark Rare Disease Day 2012, GRDO collaborated with European Rare Disease Alliance, Eurordis, to produce a short awareness-raising video. The video features six people from Ireland, each with a different rare condition. To watch the video and find out more see www.grdo.ie or www.rarediseaseday.org.

Further information:

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