

*For Immediate Release*

## Veteran Actress Launches Rare Diseases Week 2009

Former Fair City actress, Joan Brosnan Walsh, today (Feb 20) helped launch Rare Diseases Week 2009 which will run from Saturday 21<sup>st</sup> February until Saturday 28<sup>th</sup> February to highlight issues faced by patients with rare diseases and disorders. A joint collaboration between the Genetic & Rare Disorders Organisation (GRDO); the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI) and the Medical Research Charities Group (MRCG), sees Ireland extend on International Rare Diseases Day which takes place on February 28.

The actress, who played Mags Kelly in the Irish soap for 20 years, was diagnosed with the rare condition, Motor Neurone disease last year. Speaking about Rare Diseases Week, Joan said that it was hugely important to communicate the real and often unknown difficulties that rare disease patients face. "When you discover that you have a rare disease, it's life-changing and it's hugely important to have access to accurate information as well as suitable support for both you and your family. In fact, getting diagnosed properly in the first place can often be a struggle. It took almost nine months for me to receive a diagnosis. I hope that through Rare Diseases Week, we can bring patients, policy makers and medics together to work towards a National Plan for people with Rare Diseases in Ireland."

Speaking about the week, Avril Daly, Chairperson of GRDO, said; "There are between 6,000 and 7,000 identified rare diseases worldwide and about 140,000 people in Ireland are affected; a significant number when viewed collectively. So while the conditions themselves are rare, those affected are spread through every community in the country. There are many voluntary groups in Ireland and in the EU offering much needed information and support to those living with these conditions. Rare Disease week gives us the opportunity to inform the public of these supports and to highlight the significant issues patients are encountering specifically with regard to delays in access to accurate diagnosis and appropriate treatment for their conditions."

Eibhlin Mulroe, CEO, IPPOSI says the prevalence of rare diseases in Ireland is significant and the current low level of awareness and recognition of rare diseases is frustrating for the patient. "In November 2008 the European Commission issued a proposal for a Council Recommendation on

action in rare diseases. The document estimates that there are between 27 and 36 million people in Europe who are or will be affected by a rare condition. Doing the maths, we know that there are approximately 140,000 with a rare disease in Ireland but there are a further 200,000 Irish people who have yet to be diagnosed. Information on diagnosis, services and ongoing training for Healthcare Practitioners in identifying Rare Disease conditions is vital going forward. IPPOSI is working closely with all stakeholders; including patients, science, industry and government bodies to reach consensus on a plan. The momentum is there and we are confident that through discussions and dialogue we can build a model that works for Ireland.”

“This dialogue will begin at a joint seminar on Rare Diseases to be held in Dublin on Wednesday (Feb 25). Titled ‘Focus on Rare Diseases in Ireland: What is the National Plan?’ the seminar will examine how the country can develop a successful national plan or framework to address rare diseases” she added.

Chairman of the MRCG, John McCormack, says the meeting will be “a hugely important opportunity for the rare disease community to come together to discuss the current situation in Ireland. We will have a number of presentations from experts from other Member States in the EU who have successfully implemented National Plans for Rare Disease in their own countries. We hope to learn from their experiences, avoid any pitfalls and work with all stakeholders to ensure the development and implementation of a national plan for rare diseases at the earliest opportunity. Irish patient groups are funding significant medical research in this area which, it is hoped, will benefit Irish patients in the years to come. A National Plan for Rare Diseases can only support this work.”

With patients giving first-hand accounts of their own experiences, the seminar will give an insight into the difficulties faced by rare disease patients in Ireland regarding information, diagnosis and treatment.

Rare Diseases Week will culminate with a family day organised by GRDO – ‘Patient Care: A Public Affair’ - from 11am-1pm on Saturday (28 Feb) for rare disease patients and their families at the Mansion House in Dublin. There will be over 20 patient organisations in attendance to allow patients to learn more about support services available to them while children will be entertained by clowns, face painters and a musical workshop.

Rare Diseases Week is supported by Genzyme Ireland which employs over 450 people at their biotechnology facility in Waterford.

- For more information see [www.rarediseaseweek.ning.com](http://www.rarediseaseweek.ning.com)

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### **Note to Editors**

**The Genetic and Rare Disorders Organisation (GRDO)** is run by volunteers and acts as an advocate for the voluntary sector concerned with genetics by creating awareness and providing information on genetic disorders to policy makers and health officials in order to achieve a high quality of services for those directly affected by genetic conditions and their families. It also acts as a watchdog in relation to legislation concerning disability to ensure the rights of people with genetic conditions are protected.

**The Irish Platform for Patients' Organisations, Science and Industry (IPPOSI)** has a special interest in the rare disease area given that one of its strategic objectives is to address, together with key stakeholders - patients' organisations, scientists and industry (and where possible with State Agencies) - policy, legislation and regulation around the development of new medicines, products, devices and diagnostics for unmet medical needs. IPPOSI works to smooth the path in Ireland for new medicines and therapies to move from basic science in laboratories to the patients who need them. This is achieved through expertise, dialogue, consensus building, networking and influencing.

**The Medical Research Charities Group (MRCG)** informs and supports charities in Ireland in the development of their medical research. It works to raise the profile of medical research, increase funding, and ultimately alleviate suffering and mortality caused by illness. Since 2006, the MRCG charities have been co-funding research projects with the Health Research Board (HRB), made possible by an allocation from the Department of Health and Children. While the scheme does not focus solely on rare diseases a number of research projects in the area have been funded.

**Genzyme Ireland** is one of the world's leading biotechnology companies and is dedicated to making a major positive impact on the lives of people with serious diseases. The company's products and services are focused on rare inherited disorders, kidney disease, orthopaedics, cancer, transplant and immune disease and diagnostic testing. Genzyme has a substantial development programme focused on these fields, as well as cardiovascular disease, neurodegenerative diseases and other areas of unmet medical need.