

Pre-Budget Submission 2013



Today's Health Research | Tomorrow's Healthcare
14th November 2012

1. Executive Summary

The Medical Research Charities Group (MRCG) is an umbrella group of 31 charities that seeks to generate dynamic medical research in Ireland, driving a greater understanding of how illness can be prevented, how it can be diagnosed earlier and treated more effectively with the ultimate goal of improving the nation's health.

In its 2013 pre-Budget Submission the MRCG presents its case for ensuring priority investment for medical research, which will deliver patient care, public health service transformation and economic and enterprise development. A well-functioning medical research infrastructure will ultimately help patients, the health system and the economy.

2. Medical Research Charities Group (MRCG) Position

The MRCG want to ensure that there is a dynamic medical research environment in Ireland. To that end we are prioritising three areas of focus for 2013:

- The **MRCG/Health Research Board Joint Funding Scheme** needs to be continued to be supported at the existing levels of funding. This scheme provides vital funding for health research in Ireland and represents good value for money since patient medical charities provide 50% of funding for this scheme.
- **Improved support structures** for medical research, in particular the appointment of a full time **Director of Research** within the Health Service. This post is particularly needed now to deliver Government policy on health research, to safeguard health research in the on-going reorganisation of our health services and vitally, to ensure we retain the highest calibre of health researchers going forward and that health research is well positioned to support the enterprise agenda in Ireland. A strategy on **Patient Data** and its role in terms of research is also of paramount importance.
- The development of a robust and effective **National Action Plan on Rare Diseases** must be prioritised by the Government in the forthcoming budget. Such a plan is required before the end of 2013 and is an EU wide obligation. Patient groups/medical charities will not accept a 'virtual plan' on rare diseases.



The MRCG believe that during a time of recession the Government must still invest in medical research, to first and foremost assist patients, while at the same time benefitting the smart economy through the creation of jobs and the development of medical research expertise.



PRIORITY 1

Increasing Investment for Medical Research and Maintaining the Health Research Board (HRB) / MRCG Joint Funding Scheme

Facilitating and nurturing research in the health system is undoubtedly challenging, especially in a resource-limited environment, but there is a valid case to be made that this is the very time when investment in research can reap dividends. In addition to driving better health outcomes for individuals, communities and populations, investment in health research results in direct cost savings, improved reallocation of resources, objective and concrete data on access, quality, cost and outcomes, improved cost effectiveness and innovative models for the delivery and financing of healthcare.

The MRCG believes that **medical research in Ireland should be a key area of investment for the Government**, especially during a time of recession, as it assists patients, while also benefitting the smart economy through the creation of jobs and expertise.

The MRCG is a critical player in health research in Ireland, to date our members have contributed **€60 million over 6 years in patient focused research**. Currently over €900,000 in funding is provided annually for health research under the Joint Funding Scheme run by the HRB, this €900,000 is matched euro for euro in funding from MRCG member charities ensuring huge value for money. This funding allows charities to carry out health research that they would not be able to fund on their own. It also provides valuable opportunities for researchers to gain experience, thereby contributing to the knowledge economy.

There needs to be **on-going investment by the State in health research**, in order to improve the care of Irish patients and contribute to the wider economic gain. The Government must not only recognise the importance of investment in this area but also maintain investment in medical research, particularly for the Joint Funding Scheme through which our members gain valuable and vital funding.

PRIORITY 2

Improved support structures for Medical Research

Research must be embedded in the health system, likewise the health system must be a good place to carry out clinical research and there must be excellent practices and policies to support this. For this to happen the Government must urgently address the lack of leadership within the health service for the medical research agenda in this country.

The MRCG are once again calling on the Government to appoint a full time **Director of Research within the Health Service**, this post is particularly needed now for a number of reasons. Firstly, to deliver Government policy on health research. Secondly, to take a **leadership role** in incentivising and supporting clinicians and hospitals to carry out more medical research and raising awareness of the impact of health research among health practitioners. Thirdly, to **promote positive health research case studies** to enhance our reputation in this area and to ensure Ireland **retains the highest calibre of health researchers going forward**.

Increasing numbers of researchers and academics are choosing to leave Ireland because of the **lack of investment in research** and the **loss of protected time for research**. These researchers, once they leave Ireland, will bring their expertise, their international research funding and graduate research opportunities with them. This is an extremely worrying situation for us as a small country, the loss of these researchers will have a huge impact on medical research in general, and on patients in particular.

Among the MRCG members are a number of charities representing **rare diseases**. Research into rare diseases is frequently instigated by treating clinicians who see first-hand the great need for improved understanding and treatment of such diseases. If these clinicians decide to leave Ireland due to the adverse conditions facing them we will lose their expertise, research experience and funding that they have secured.

This is a critical position for us to be in and is at odds with the Government's enterprise agenda.

Research and innovation in a primed health system have a vital role in **supporting enterprise development in Ireland**, creating jobs and delivering significant economic benefits to the exchequer through direct and indirect savings. Developing and maintaining a high quality health research system provides opportunities to engage with private enterprises in areas such as pharmaceuticals, medical devices, diagnostics, services science, e-health and assisted living technologies and thereby benefitting the smart economy.

The Research Prioritisation Exercise recently undertaken by Forfás targets public investment towards research based on potential for economic return. This focus on translational research and commercialisation opportunities combined with a **lack of investment into early stage basic research** will damage the pipeline for early drug development and will also damage the quality and reputation of the core biomedical research environment in Ireland.

There also needs to be a **strategy around patient data** and its role in terms of patient research. **Patient Registries** are vital for medical/health research, yet there is no national policy or adequate recognition of the role of patient registries in Ireland. The work of many patient registries remains undervalued and **underfunded by Government**. Some are barely surviving and are in real danger of reducing their work or even closing.

Patient registries provide vital information on issues such as the number of people suffering from a disease; where treatment centres should be located and whether the survival ages of patients are increasing or decreasing (a key indicator of quality of patient care). Patient registries are recognised internationally as a **vital prerequisite for good quality health research**, yet there is no coherent policy approach for their development or support in Ireland.

The need for an effective and resourced National Plan on Rare Diseases

There is considerable fragmentation in current services and treatment for rare diseases. Ireland needs an effective **National Plan on Rare Diseases** that will help ensure patients and their families have access to early diagnosis, that vital and accurate information and support is provided and centres of expertise are available in Ireland, where they do not exist at the moment. Such a plan is required before the end of 2013 and is an **EU wide obligation**. Patient groups/medical charities will not accept a 'virtual plan' on rare diseases.

In the European Union, a disease is defined as rare when it affects less than 1 in 2000 people. In **Ireland it is estimated that 6-8% of the population has a rare disease** (around 280-370,000 people). In other words up to 1 person in 12 may have a rare disease at some stage in their life in Ireland.

Patients with rare diseases must not be denied access to new and innovative therapies purely because of budget consideration. Savings made by the Government through new agreements with the pharmaceutical industry must be made available to purchase new and innovative therapies/drugs and to supporting vital health research in Ireland.

The National Plan on Rare Diseases has the potential to address these issues if it is given sufficient priority by the Irish government.

"In a time of recession health research should be a key area for investment by the Government, to first and foremost assist patients, while at the same time benefitting the smart economy through the creation of jobs and the development of expertise. The MRCG/HRB Joint Funding Scheme is of huge importance to our members and we are calling on the Government to recognise the significance of this scheme and the vital role the HRB plays in supporting medical research in Ireland,"

- Philip Watt, Chairperson of the Medical Research Charities Group and CEO,
Cystic Fibrosis Association of Ireland.



www.mrcg.ie

For further information please contact us on: **01 4912044/2045**

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