

Medical Research Charities Group

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Unity is our Strength

Today's Health Research Is Tomorrow's Healthcare

**Medical Research Charities Group
Pre-Budget Submission Budget
2011**

*The future for patient focussed medical research
in Ireland in a recessionary environment*

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Pre-Budget Submission Summary

1. The Medical Research Charities Group (MRCG) is advocating for Continuity of Joint Funding for Patient led Research.

- We ask that the Government maintains €1m in funding to continue the existing research co-funding partnership between the Health Research Board and MRCG in the 2011 Budget. €1m of Government funding is matched by €1m of funding from charities to increase the research capacity in Ireland.
- MRCG Members have contributed €60m over the last 6 years in patient focused research.
- MRCG Charities provide employment for approximately 100 researchers.

2. We are also advocating for improvements which will create a better Irish Research Environment.

2.1 Commitment to National Strategy for Rare Disease

2.2 Greater Support for National Center for Medical Genetics

1. Continuity of Joint Funding for Patient led Research

Continuation of the existing €1m revenue funding allocated to the HRB for MRCG projects

Between 2005 & 2010 MRCG members will have invested a total of €60m in medical research. This valuable contribution has been recognised by the Minister of Health and the Department of Health & Children. In February 2006 the Minister announced the allocation of €1m to the base of the HRB budget for the co-funding of medical research projects with the MRCG charities. As a result of this MRCG members have been able to co-fund 56 high calibre patient focussed research projects to date.

The MRCG are requesting that the existing annual funding stream of €1m be maintained and ring-fenced in the budget specifically for the co-funding of medical research projects.

The continuation of this scheme will allow MRCG members and the exchequer to leverage philanthropic funding and guarantee better value for each Euro invested. **MRCG charities provide employment for approximately 100 researchers driving cutting edge, patient outcome focused research.** This direct employment has many knock-on benefits and contributes to the employment of many others e.g. provision of research infrastructure. Improved treatments through research will result in long term savings to the economy while increased participation in clinical trials has an immediate effect on increasing the quality of care in the clinical environment.

Investment in research is critical to the development of a knowledge economy in Ireland. Ireland lags behind other OECD Countries in terms of medical research spend. The OECD average spend on health research as a percentage of GDP is 0.12%, whereas Ireland's spend on health research is just 0.06%.

- The development of medical research in partnership with medical charities has created immense value for Ireland both in the quality and quantity of research being carried out
- Co-funding has created high-end career opportunities for many researchers and has been responsible for a number of successful internationally recognised projects
- It has acted as the catalyst for the funding of research by new charities
- The existing co-funding scheme has developed a strong partnership between the Health Research Board (HRB) and the MRCG and the reciprocal knowledge and skills acquired through this partnership has created value much greater than the funding itself
- Patient funded research looks for improved patient outcomes and treatments
- MRCG charities are skilled in securing philanthropic and private enterprise funding for medical research
- Co-funding has brought together and added skills to medical charities in research processes

2. Creating a Better Research Environment in Ireland

Health Research spend in Ireland is well below the OECD average. We believe that the Irish Research Environment could be more effective if some changes were made that involved more efficient use of existing resources. The Medical Research Charities Group has a special interest in Rare Diseases and Genetics - as many of our member organisations support patients with rare disease and also diseases of a genetic origin.

We believe that commitment to the following areas would significantly improve the Research Environment in Ireland and the quality of life for many patients.

2.1 Commitment to National Strategy for Rare Disease

Ireland has signed up to the development of a National Strategy for Rare Disease. 157,500 people in Ireland are currently affected by a rare disorder - some 3.5% of the population.

A National Strategy for integrated service delivery would aim to create efficiencies in expenditure and service allocation. It would:

- Help to make the most efficient use of the limited resources available
- Support the Government's research agenda, including strengthening international research
- Facilitate early, correct and timely diagnosis and treatment which will offer improved health for people with Rare Diseases.

A National Strategy for Rare Diseases should include the following:

- Establishment of **Centres of Expertise** for Rare Diseases. Centres of Expertise are care centres that bring together a group of multidisciplinary specialized competencies specialising in a single Rare Disease or group of Rare Diseases. **Centres of Expertise reduce costs in healthcare systems.**
Centres of Expertise will contribute to
 - Timely diagnosis, a reduction in misdiagnoses and subsequent unnecessary treatments
 - Appropriate follow up care
 - Access to social support
- Access to **Orphan Drugs (drugs for rare diseases)**
- Access to new **diagnostic and therapeutic** procedures
- Dedicated funding for **Rare Disease Research**
- **International cooperation** in Rare Disease research
- **Greater scientific knowledge** about all Rare Diseases, not only the most "frequent" ones
- Facilitation of **network of patient groups** to share their experience and best practices
- **Equal Access to drugs, therapies and treatments** that will provide optimum medical and health benefits for all Rare disease patients
- Support for the most isolated patients and their families - particularly through the provision of a **Rare Disease helpline**

2.2 Greater Support for National Center for Medical Genetics

The National Centre for Medical Genetics (NCMG) is the national provider for genetic testing and counselling, and is based in Our Lady's Hospital for Sick Children in Crumlin. The NCMG plays an active role in medical research and the support of medical research in Ireland. Considerable work is being done in the areas of hereditary heart disease, autism, muscular dystrophy, Huntington's disease, cystic fibrosis and many more genetic conditions.

The NCMG It has never been resourced adequately and is entirely part of Our Lady's Hospital, Crumlin, despite being a national service, and despite 40% of the NCMG's patients being adults.

The NCMG needs to become an autonomous organisation within the HSE, with its own budget and board directorate. In that way, its ability to deliver genetic services would not be compromised by restrictions placed on Our Lady's Children's Hospital.

The NCMG has experienced significant difficulties in maintaining services due to cuts to the Hospital's budget. Due to an embargo on filling vacant posts and maternity leave absences, there is a serious level of understaffing at the NCMG. The NCMG is significantly under resourced, with 75% less staff than that provided for a unit in the UK covering 4.2 million. **Extra recruiting and training required if the NCMG is to provide the required service that meets international standards.**

As services are curtailed, more and more genetic samples are being sent out of the country for analysis. The costs for the processing of these samples is still being incurred by the state but are being charged to the individual hospital. The NCMG proposes that **the Centre be resourced so that all samples for genetic testing from HSE services should be sent to the NCMG, where the samples can be appropriately triaged, and for many samples tested in the NCMG's own laboratories.** This change in policy would save the HSE considerably on the current major cost of sending samples abroad for genetic testing.

Background

The Medical Research Charities Group (MRCG) is an umbrella group of medical research and patient support charities, which originally formed to represent the joint interests of charities specialising in restoring health through medical research, diagnosis, treatment and where possible, the prevention of disease. A core belief of the group is that today's health research is tomorrow's health care.

The MRCG believes that patient organisations should lead and stimulate the critical medical research needed by patients, and provide leadership and support to charities in Ireland that are engaged in medical research.

The budget needs to recognise the important role played by outcome focused research that will improve the quality of life of patients and contribute as a whole to the knowledge economy.

The budget also needs to recognise the important roles patients and patient organisations play in health research and to affirm the importance of maintaining and improving health research effectiveness. Research discoveries are central to achieving the goal of extending healthy lives. Research into the cause of diseases, methods for prevention, techniques for diagnosis, and new approaches to treatment has increased life expectancy, reduced infant mortality, limited the toll of infectious diseases, and improved outcomes for patients with all forms of chronic diseases. It is a recognised fact that patient orientated clinical research tests new ideas and makes rapid medical progress possible.

Collaborative partnerships among communities of patients, their physicians, and teams of researchers to gain new scientific knowledge will bring tangible benefits for people in this country.

Appendix

List of MRCG Member Charities

Alpha One Foundation
Alzheimer Society of Ireland
Arthritis Ireland
Asthma Society of Ireland
Bee for Battens
Brainwave: The Irish Epilepsy Association
Children's Leukaemia Research Project
Children's Medical & Research Foundation
Cystinosis Foundation Ireland
DEBRA Ireland
Diabetes Federation of Ireland
Duchenne Ireland
Fighting Blindness
Friedrich's Ataxia Society of Ireland
Friends of St Patrick's Hospital
Heart Children Ireland
Irish Cancer Society
Irish Heart Foundation
Irish Osteoporosis Society
Irish Thoracic Society
Meningitis Research Foundation
MS Ireland
Muscular Dystrophy Ireland
Parkinson's Association of Ireland
Research & Education Foundation, Sligo General Hospital
Sightsavers International (Ireland)
St Vincent's Anaesthesia Foundation
The Cystic Fibrosis Association of Ireland
The Mater Foundation

Reports relevant to Investment in Medical Research

The Department of Health & Children in its Strategy for Health Research in 2001 provided a framework for the development of health research to enhance health and quality of life and help ensure that Ireland's research compares favourably with the rest of the world. It highlighted that an active research community working close to the delivery of health care in clinical settings, laboratories, the community, third-level institutions and the healthcare industry was critical to the improvement of the quality of health services generally. The same strategy outlined that health research was vital for professional development and career satisfaction of health service staff and was also important for the translation of ideas into medical and IT products that would add value to our economy. The research strategy committed the government to enhancing substantially its support for "science for health" – investigator-led, bottom-up research – and for the first time to establish and support a research and development function in the health system.

The First Report on the Strategy for Science Technology & Innovation (SSTI) 2006-2013 outlined the need for a strong research culture if the health service is to offer a world-class standard of care to patients and retain professionals of the highest quality. It acknowledges that the system also needs to harness research to find better ways of improving the health of the population and delivering more efficient and effective healthcare.

The Advisory Council for Science Technology & Innovation report on health research (2006) identified that the total medical research expenditure while significant, was low by international comparisons. It identified a requirement to ensure that the health research needs of the Irish population were addressed by top-quality, adequately-funded research, both through the budget of the Department of Health and Children and under the Government's Strategy for Science, Technology and Innovation, 2006-2013. It also highlighted the significance of the potential benefit of health-related research to the social and economic well-being of the population.

The Department of Health and Children Action Plan for Health Research 2009-2013 outlines the crucial importance of health research to this country and identifies health research as a key element of the healthcare system. It also recognised that major investment in medical research in Ireland will provide maximum health, social and economic returns.