

Charities Call on Government to Ramp Up Investment in Medical Research, to Streamline Access to New Life-Changing Therapies and to Develop National Patient Disease Registries

- Group Publishes *Manifesto for Medical Research* and Demands Urgent Passing of Human Tissue, and Health Information & Patient Safety Bills before Dáil's Dissolution -

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The Medical Research Charities Group (MRCG), representing a coalition of more than 30 charities, has today called for investment in medical research to be ramped up if patients are not to miss out on new cures and treatments, and if we are not to lose our brightest and best researchers to more attractive research opportunities abroad.

The Group made the call as it published its *Manifesto for Medical Research* and urged political parties to pledge to make medical research a key priority should they form part of the next Government.

Among the key actions the MRCG is demanding are:

- **Investment:** a commitment to ramp up funding of medical research and the appointment of a HSE research tsar who would have responsibility for championing research across the health services
- **Therapies:** a streamlined process for the approval of innovative and emerging therapies so that once given the green light by the European Medicines Agency, patients can benefit without delay
- **Registries:** the development of National Patient Disease Registries, such as those in place for cancer and cystic fibrosis, is vital. This would ensure that information, such as numbers diagnosed, survival rates, geographic variations, etc., across a range of conditions is captured, and trends and variations tracked to better inform policy and service development
- **Legislation:** the urgent passing of the Human Tissue Bill and the Health Information & Patient Safety Bill is required to provide important assurances for members of the public in the areas of research oversight and ethics, data protection, use of human tissue, etc.

- **Rare Diseases:** a detailed implementation framework is essential for the National Rare Disease Plan launched in July 2014, but which has yet to be even incorporated in to the Health Service Executive (HSE) Service Plan
- **Genetic services:** a national policy on the future of genetic services in Ireland needs to be drawn up to address key issues such as clinical genetic services and counselling which play a key part in the diagnosis and treatment of those with rare diseases in Ireland.

Philip Watt, Chairperson of the Medical Research Charities Group, believes patients will be the real losers if Government does not take vital action now to prioritise medical research:

"Medical research has been pivotal in increasing life expectancy, reducing infant mortality, limiting the toll of infectious diseases, and improving outcomes for patients. Clearly, without significant investment, Irish patients will be left at a serious disadvantage. Patients in very challenging disease areas will have to go abroad if they want to access clinical trials for promising therapies that could make a huge difference to their lives. Patients will also be left in the slow lane when it comes to accessing treatments and therapies in the early stages of development. It is simply not right that Irish patients should be treated as second class to citizens in other European countries that really are pushing the boundaries and the possibilities of research.

"There have been rapid advances in the development of new therapies in recent years that have the potential to offer a major extension to quality of life and, indeed, life itself. It is evident, in the light of a number of recent cases where patients have not been able to access vital treatments in a timely way, that we need more appropriate decision criteria and a much more streamlined approach to reimbursement of new treatments and technologies. Patients, often in a very vulnerable state, should not be have to beg for the treatment that they deserve, caught in the crossfire of price negotiations between Government and the pharmaceutical industry."

Mr Watt adds that there is a pressing need for leadership to be provided in our health services if we are to hold on to talented researchers:

"The lack of leadership within our health services for medical research, and the loss of protected time to undertake it, also needs to be urgently addressed. Clinical research needs to be at the core of our health services, embedded within every team and every department, with clinicians supported and incentivised to undertake that work. The appointment of a research tsar by the HSE, with a ring-fenced budget, and a clear vision and strategy, would bring a much-needed focus to this area. It would be an important first step in demonstrating Government's commitment to best practice in clinical treatment, to best innovation in science, and to best outcomes for patients."

Dr David McConnell, Fellow Emeritus in Genetics, Smurfit Institute of Genetics, Trinity College Dublin, and a pioneer in Ireland of recombinant DNA, also known as genetic engineering, comments:

"Medicine is being revolutionised by huge advances in genetics, immunology, imaging and diagnostics. For Ireland to keep pace with this revolution in medical science and to continue to pioneer new treatments, we need to have the very best doctors who are up to speed with the latest research in their field. This means investing in the research of the leading Irish medical scientists. Technical and scientific services in our hospitals also need to keep up with new developments. For example, it is essential that we invest in new DNA-based techniques to faster and more accurately diagnose cancers and microbial and viral infections. We also need to properly resource medical genetics services, and it is astonishing that the National Centre for Medical Genetics has been downgraded to a hospital department. Our research capacity is being damaged severely through being starved of resources and funding. When more than 30 charities involved in medical research come together to issue a clarion call for urgent action, the Government really needs to listen."

Dr Ray McDermott, Consultant Medical Oncologist, Tallaght Hospital and St Vincent's University Hospital, and Clinical Lead of the All-Ireland Co-operative Oncology Research Group (ICORG), adds:

"We need to establish clinical trials as a routine aspect of care, and that requires enhanced funding that is ring-fenced. Trials not only allow access to new therapies but are associated with better quality of care for patients as they have staff dedicated to them. In order to enhance research, we need protected time for clinicians who wish to be involved and we need a guaranteed career structure for staff nurses and data managers who are involved in research so that it becomes an attractive option. We also need investment in research networks such as ICORG to allow access to trials for patients near to where they live."

To download the manifesto, or for more information on the work of the MRCG, visit www.mrcg.ie

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About the Medical Research Charities Group

The Medical Research Charities Group (MRCG) is an umbrella body of more than 30 medical research and patient support charities, which represents the joint interests of charities specialising in restoring health through medical research, diagnosis and treatment and, where possible, the prevention of disease. Its mission is to generate a dynamic medical research environment in Ireland. For more information, see www.mrcg.ie

The members of the MRCG are:

1. Alpha One Foundation
2. Alzheimer Society of Ireland
3. Arthritis Ireland
4. Asthma Society of Ireland
5. Breakthrough Cancer Research
6. The Temple Street Foundation
7. CLAPAI – Cleft Lip and Palate Association of Ireland
8. COPD Support Ireland
9. Croí West of Ireland Cardiac Foundation
10. Cystic Fibrosis Ireland
11. Cystinosis Ireland
12. DEBRA Ireland
13. Diabetes Ireland Research Alliance
14. Duchenne Ireland
15. Epilepsy Ireland
16. Fighting Blindness
17. Friends of the Rotunda
18. Heart Children Ireland
19. Irish Cancer Society
20. Irish Heart Foundation
21. Irish Nephrology Society
22. Irish Thoracic Society
23. MS Ireland
24. Muscular Dystrophy Ireland
25. Research & Education Foundation: Sligo General Hospital
26. Royal Victoria Eye and Ear Research Foundation
27. St John of God Research Foundation
28. St Patrick's Hospital Foundation
29. St Vincent's Anaesthesia Foundation
30. The National Children's Research Centre
31. The Heartbeat Trust
32. The Mater Foundation
33. The Rutland Centre
34. The Saoirse Foundation