

The MRCG represents  
**1.2 million patients** from  
the following member  
organisations

Alpha One Foundation  
Alzheimer Society of Ireland  
Arthritis Ireland  
Asthma Society of Ireland  
Bee for Batters  
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

## OUR PRIORITIES FOR IMPROVED RESEARCH ENVIRONMENT IN IRELAND

**Maintain €1m in funding to continue the existing co-funding partnership between the Health Research Board and Medical Research Charities Group (MRCG) in the 2011 Budget.**

- €1m of Government funding is matched by €1m of funding from charities giving more value for every government euro spent
- MRCG Members have contributed a total of €60m over the last 6 years in patient focused research.
- MRCG Charities provide employment for approximately 100 researchers - plus indirect employment for suppliers and support services

**Creating a better Research Environment — Health Research spend in Ireland is well below the OECD average**

- Commitment to National Strategy for Rare Diseases
- Greater Support for the National Centre for Medical Genetics

## THE MRCG/HRB JOINT FUNDING SCHEME FACILITATES HIGH QUALITY MEDICAL RESEARCH

Many patient support charities have been encouraged to set up a formal research funding scheme as a result of the HRB MRCG Joint Funding Scheme.

**Brainwave, The Irish Epilepsy Association**, is one of the many charities which has benefited from the scheme.

“Brainwave was encouraged to set up a formal research program as a result of the Joint Funding Scheme. Brainwave now has the capacity to fund research projects that previously would have been beyond our reach” **Mike Glynn CEO Brainwave The Irish Epilepsy**

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## Maintain Joint Funding Scheme

State currently invests €1m a year in the existing MRCG/HRB Joint Funding Scheme.

This accounts for 56 quality 3 year cycle research projects to date.

MRCG charities provide employment for 100 researchers.

Co-funding ensures the state gets more value for each research euro invested

MRCG charities are skilled in securing philanthropic and private enterprise funding for medical research

*“Patient led medical research has made a huge contribution to the quality and quantity of research taking place in Ireland today”*

## Improve Research Environment in Ireland:

Commitment to National Strategy for Rare Diseases

Support for the National Centre for Medical Genetics.

Dedicated Funding Stream for Research into Rare Disease and a commitment to supporting Orphan Drugs (drugs for rare

## JOINT FUNDING SCHEME RESEARCH PROJECTS WORKING TOWARDS NEW TREATMENTS

Emma Fogarty is 26 years old and lives with her parents in Co. Laois. She was born with Recessive Dystrophic Epidermolysis Bullosa(EB).

Emma was awarded with a **Rehab People of the Year Award** in September of this year.

Emma has been confined to a wheelchair for the last 3 years. She is unable to eat most things due to

restrictions in her throat.

She has to endure blisters in her eyes, the possibility of leg fractures due to osteoporosis, or having daily painful dressings.

**Debra Ireland** provides support to people with EB and is currently funding research programmes in Trinity and NUI Galway. This research is making solid progress towards the

development of treatments for the condition.

“The research projects funded by Debra Ireland provide hope to all of us with EB that better means of pain management and treatment will be developed and ultimately a cure for



## UNIVERSITY COLLEGE CORK RESEARCHERS LEADING INNOVATIVE INTERNATIONALLY RECOGNIZED PROJECTS

Cystinosis is a genetic metabolic disease causing life-long degeneration of all organs, beginning in early childhood with kidney failure.

Since 2005, Dr Patrick Harrison's research group in UCC has been developing a technique called ZFN-HDR to first cut, and then repair the mutated genes which cause Cystinosis.

In January 2009,

with a €120K grant received from **Cystinosis Foundation Ireland** and the HRB, through the Joint Funding Scheme, they started to apply ZFN-HDR to mutations in the Cystinosis gene.

After presenting the group's preliminary data at a Cystinosis Research Symposium in California in April this year, Dr Harrison secured an additional \$150K from a US-based Cystinosis charity to

extend the research activity in Cork.

Two teams of researchers are now employed at UCC, creating high level employment and leading innovative,



**Cork Cystinosis Research Team**

Dr Patrick Harrison, Ciaran Lee, Dr Martina Scallan, Katrin Kaschin, Jenifer Hollywood