

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.
- MRCG charities indirectly employ 100 researchers.
- MRCG advocating to maintain the existing funding of €1m p.a. and will match any additional funds the Government can allocate to the MRCG for patient driven medical research
- Partnership with patient groups makes good political sense.
- Patient funded research looks for improved patient outcomes and treatments.
- Research is encouraged across all disciplines and disease types.

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

Maintain a research friendly environment by:

- Maintaining or increasing funding for dedicated health care research.
- Developing a national genetics testing and counselling service.
- Developing patient registries.
- Protecting research time for healthcare professionals.
- Supporting the development of biobanks and a gene library

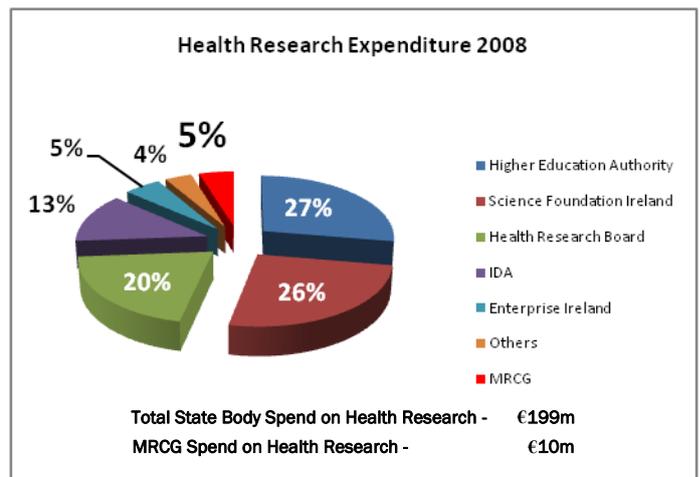
MAINTAIN €1M FUNDING FOR RESEARCH PARTNERSHIPS

The MRCG is advocating that the Government maintain €1m in revenue funding to continue the existing research co-funding partnership between the Health Research Board and MRCG in the 2010 Budget. If any additional funds come available for patient research the MRCG will endeavour to match these funds.

Medical charity members of the MRCG have made a very significant contribution to medical research in Ireland by investing €60m over the last 6 years in patient focused medical research. This is equivalent to approximately 5% of the State's total health research expenditure.

This significant contribution to medical research in Ireland and to the advancement of the knowledge economy needs to be recognized. Partnerships between philanthropic organizations and the State need to be encouraged and developed.

Patient advocated and co-funded medical research will



ensure that cutting edge outcome driven, patient focused research will take place at a substantially lower cost to the exchequer. A lower cost does not imply a lower research quality. All MRCG co-funded projects follow the HRB selection criteria. Projects are selected by open competition; all are peer reviewed, and are of world class quality. Collaboration with other world centres of excellence is encouraged. Smaller patient groups such as those representing rare diseases

are encouraged and supported in developing research programmes.

Medical research needs to maximise the opportunity for the translation of breaking science into the development of new drugs and treatments. These developments are very important issues for patients and their families.

The development of clinical trials will in the short term improve the quality of patient care and in the long term will result in better patient outcomes.

A RESEARCH FRIENDLY ENVIRONMENT NEEDS TO BE MAINTAINED

MRCG recognises that the health research environment in Ireland is very complex with multiple participating organisations that individually make valuable contributions to the success of medical research and the knowledge economy as a whole.

This encompasses funding organisations, research establishments, academia, health care services and their personnel.

MRCG believes that if progress is going to be made in developing health research and the knowledge economy

then the financial security of the various contributor bodies, such as HRB & SFI need to be closely monitored and supported. In addition essential research infrastructures have to be maintained or put in place.

“The HRB Joint Funding Scheme is vital for patient focussed research”

RESEARCH LEADS TO CLINICAL TRIALS & NEW TREATMENTS



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ASH Ireland
Asthma Society of Ireland
Brainwave: The Irish Epilepsy Association
Children's Leukaemia Research Project
Children's Medical & Research Foundation
Cork Cancer Research Centre
Cystic Fibrosis Research Trust
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
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
Research Institute for a Tobacco Free Society
Sightsavers International (Ireland)
The Cystic Fibrosis Association of Ireland
The Mater Foundation

Alpha-1 Antitrypsin Deficiency (Alpha-1) is an inherited genetic condition and along with Cystic Fibrosis is one of the most common genetic disorders in Ireland which affects the lungs and the liver. The Alpha-1 Foundation has carried out research showing that up to 3,000 people on the island of Ireland have Alpha-1 which is either undiagnosed or misdiagnosed as something else. Eleven years ago, Josephine's brother, then aged 47, was diagnosed with Alpha-1. Of the four siblings tested, three had Alpha-1. One of Josephine's sisters died before the family was tested for the Alpha-1, and they do not know if she also had the disorder.

Alpha-1 affects people to different degrees. Day to day, Josephine manages her life and home and tries not to let the disease have too great an effect. However, because of her condition, Josephine suffers from emphysema and has to be careful not to exert herself too much. Doing so leaves her

out of breath and unable to perform other tasks. Josephine uses medication daily through inhalers and has to be careful of contracting colds and the flu. Josephine is lucky that her liver is not yet affected by the disease.

Two years ago, Josephine was approached by her consultant to take part in a clinical trial for a medication for Alpha-1. At the time, Josephine was one of only three Irish participants. Following on from her participation in the trial, Josephine has been on medication for her disease and has found the effects beneficial. Josephine's case illustrates that patient can benefit from research by participating in clinical trials.

Emma is 25 years old and lives with her parents in Abbeyleix. She was born with Recessive Dystrophic Epidermolysis Bullosa. E.B is a life threatening genetic condition. Emma has been confined to a wheelchair for the last 2 years and no longer lives an independent life. Doing the simple things like

turning around in bed, opening a can of Coke or closing buttons are the hardest. Every day brings new burdens, like, waking up in the morning to find blisters in her eyes and not being able to open them, the possibility of leg fractures due to osteoporosis, or having daily painful dressings. She is unable to eat most things due to restrictions in her throat.

Emma knows that there currently is no cure. A cure for this condition would bring an end to all the pain endured by patients with EB.

Further research would mean that in the future a cure for EB could possibly be found and new means of pain management and treatment could be developed. Research gives hope and comfort that life may not end prematurely.



CHARITY DEVELOPS MEDICAL RESEARCH INSTITUTE

€2.9M COMMITTED
DURING 2009

In October 2008 Fighting Blindness became the first patient charity to establish a medical research institute, the **Fighting Blindness Vision Research Institute**.

The Institute is based in the National Institute for Cellular Biotechnology on Dublin City University Campus and directly employs scientists and staff to carry out vision research.

The purpose of the Institute is to consolidate Fighting Blindness research activities, and act as a nucleus for building up a national and international research network. As well as funding its own scientists, the Fighting Blindness Vision Research Institute (FBVRI) continues to fund projects at 12 other universities, hospitals and colleges.

During 2008, the Irish Cancer Society committed €2.9m to cancer research. This money was used to fund essential clinical trials, and pre-clinical research in hospitals and universities across Ireland.

Dr Ann Hopkins from the Royal College of Surgeons of Ireland and Beaumont Hospital has just completed a three year research project funded by the Society.

Dr Hopkins in her research investigated why some tumours remain confined to the milk ducts in the breast while others break out and spread to other tissue.

By investigating cancer cells from both localised and invasive breast tumours and growing the cells in the lab, the research group have identified some of the signals that cause invasive breast cancer cells to break away from the breast and spread quickly throughout the body.

These discoveries may help

to develop new strategies to stop breast cancer from spreading.

Research in Ireland is leading to improved knowledge of cancer and ultimately leads to better treatments for patients.

Cystinosis is a very rare disease affecting 9 people in Ireland. Early diagnosis gives patients the best chance of survival and quality of life. The build up of the amino acid cystine, which causes cystinosis, damages all organs and muscles in the body. The kidneys are first affected and without specific treatment, a child will go into renal failure before his or her 10th birthday. Current medication for cystinosis only slows the deterioration process, has severe side effects and has to be administered every 6 hours. Cystinosis Foundation Ireland has been able to co-fund research projects into better medication and a search for a cure thanks to the HRB/MRCG Joint Funding Scheme.



Fighting Blindness Vision Research Institute