

Varadkar announces €850,000 investment for research into rare diseases

Five charities to provide matching funding bringing total investment to €1.9M

Minister for Health, Leo Varadkar, has announced that five charities will share €850,000 in State funding to take part in international research into rare medical conditions, including respiratory infections and retinal blindness.

The Government is investing €850,000 through the Health Research Board with matching funding provided by the Medical Research Charities Group (MRCG), bringing the total investment to €1.9 million. A total of eight projects will be supported over the next three years, bringing to 95 the projects supported through this particular scheme over the past eight years.

“This funding allows the charities to take their research activities up a level. They will be able to participate in international research projects, or fund projects which are being led from outside Ireland. It’s a practical example of collaboration between the State and the charity sector. Hopefully, the research will bring real benefits to patients in Ireland and around the world,” Minister for Health, Leo Varadkar said.

The five charities taking part are Alpha One, Cystinosis Ireland, Fighting Blindness, the Irish Thoracic Society, and the Royal Victoria Eye and Ear Hospital Research Foundation.

To date results from projects completed under this scheme include 13 healthcare innovations, 23 policy and practice influences, two patents and more than 120 peer-reviewed academic papers. Examples include a new immune therapy for cancer, potential new drugs to treat conditions such as cystic fibrosis and nephropathic cystinosis and an effective exercise programme to improve outcomes acute stroke survivors and their families.

HRB Chief Executive, Graham Love says,

‘This HRB joint funding initiative with the medical research charities group means Irish people affected by rare diseases can benefit from international research efforts to find a cure for their particular illness. Ordinarily, the HRB only funds research conducted in Ireland. However, through this scheme rare disease charities can participate in international research projects, or fund projects that are led from outside Ireland.’

Mr Philip Watt, Chairman of the MRCG says,

‘MRCG members are typically patient charities that have a strong commitment to health research to help find new and innovative therapies and to improve patient care in Ireland. The MRCG/HRB joint funding scheme means that the government provides €850,000 for health research which is matched to the same amount by patient charities. This partnership approach has resulted in wide range of important research projects that would not have otherwise occurred in cancer, fighting

blindness, cystic fibrosis, and other rarer diseases such as Alpha 1'.

A summary of projects* supported with the funding are outlined below

HRB and Alpha one will fund the Royal College of Surgeons in Ireland on two projects. Alpha-1-antitrypsin (AAT) deficiency (AATD) is hereditary disorder that worsens lung disease.

1. Dr Emer Reeves from RCSI will look at the role white blood cells play and compare difference between white blood cells in AADT patients and non-patients.
2. Prof Noel McElvaney will look at how levels of Alpha-1-antitrypsin (AAT) in blood to determine the predisposition to lung disease and other inflammatory processes.

HRB and Cystinosis Ireland will support two international projects in New Zealand and Florida.

Cystinosis is a rare, degenerative disease in which there is a build-up of an amino acid called cystine which accumulates abnormally in all cells and leads to cell death. Cystinosis slowly destroys all organs in the body, kidneys, liver, muscles, eyes, pancreas, thyroid and the brain.

1. Prof Anuj Chauhan , University of Florida will focus on the development of a contact lens to deliver medication to the eye of cystinosis patients who would normally have to use drops on an hourly basis.
2. Dr Jennifer Hollywood (Ireland) will work with Prof Alan Davidson in the University of Auckland to examine stem cells of patients to try and modify the genetic defect and see if the rescued cells can generate normal Kidney cells.

The HRB and Fighting Blindness will fund two projects on retinal degeneration which is the most common cause of blindness.

1. Dr Brendan Kennedy in UCD will test a new range of drugs to treat retinal degradation on zebrafish.
2. Dr Giuliana Silvestri from Queens University Belfast will form an All-Ireland retinal degenerations Partnership including the development of an all-island database for inherited retinal degenerations and feedback clinics for participants.

The HRB and the Irish Thoracic Society will fund a project that will investigate the impact of bile aspiration on chronic respiratory infections. Professor Fergal O’Gara at University College Cork will study the unexplained link between gastro-oesophageal reflux (GOR) and severe respiratory disease. This study will have particular emphasis on patients with cystic fibrosis.

The HRB and Royal Victoria Eye and Ear Hospital Research Foundation will fund a project at RCSI which will look at Sjoren’s Syndrome (SS) – an auto-immune disorder where the immune system attacks the secretory glands leading to severe dry eyes, mouth, skin and large intestine. In addition patients have an increased risk of developing non-Hodgkin’s lymphoma and severe pulmonary complications.

Prof Conor Murphy and Dr Joan Ní Gabhann will investigate the contribution of microRNA to mechanisms that regulate production of inflammatory cytokines, as defects in these pathways are believed to be the root cause of pathology in SS.

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