**EURETINA, Paris, September 5th: The £558 Million burden of Inherited Retinal Dystrophies (IRDs) in the Republic of Ireland and United Kingdom is largely borne by patients and their families. The IRD COUNTS study highlights the £212 Million cost of wellbeing and £123 Million cost to productivity incurred by these conditions and that the burden of these diseases is not appropriately captured by current mechanisms of health assessment.**

IRDs represent a diverse group of progressive, visually debilitating diseases for which, until recently, there have been no effective treatments.

The prevalence and impact of IRDs at a national and global level is largely undocumented. Patients, and, the organisations who represent them along with health care providers and scientists have witnessed the reality of life with an IRD and understand the impact on wellbeing, on mental health as well as the socioeconomic burden. The lack of data in this area hinders the development and commissioning of clinical services, treatments, and the planning and implementation of clinical treatment trials**.**

There is an urgent need for a stronger evidence base on the impact of IRDs. This is needed to support value-for-money to regulatory bodies for recently approved therapies, and potentially new therapies progressing through clinical trials towards market. This evidence base highlights the importance of investment in critical genetic testing services and for research that will aid the developments of treatment for unmet need.

Deloitte Access Economics was engaged by the IRD COUNTS, a patient led multi-stakeholder consortium, to estimate the disease burden and economic impact of inherited retinal dystrophies (IRDs) in the Republic of Ireland (RoI) and United Kingdom (UK) from a societal perspective – a cost-of-illness study. This approach involved estimating the number of people with IRDs in a base period (2019) and the costs attributable to IRDs in that period.

This pilot study relates exclusively to ten forms of IRDs: Retinitis Pigmentosa, Usher Syndrome, Stargardt Disease, LCA/EOSRD, Best Disease, Cone Dystrophy, Cone-Rod Dystrophy, Achromatopsia, Choroideremia and X-Linked Retinoschisis.

The study shows that in both the ROI and UK the impact on the wellbeing and productivity of the affected individual and their families was significant.

Wellbeing costs were responsible for 33.8% (€16 Million), and 38.4% (£196.1 Million) of total IRD costs in the RoI and UK respectively. Productivity costs were the second highest cost burden due to IRDs in both the RoI and the UK amounting to €9.4 Million, and £114.1 Million. Persons with an IRD in the RoI and the UK were 55.7% and 40.2% less likely to be in paid employment than the general population. In both regions IRDs resulted in a 9.6% reduction in productivity while at work.

**It also demonstrates that the financial burden is primarily borne by the affected individuals and their families.**

In both the ROI and the UK the cost attributed to health systems was low €2.2 Million (ROI) and £25.0 Million (UK) respectively. This shows that those with a vision impairment do not engage as frequently with health care professionals as they do with those providing social and psychosocial supports. However, the societal effects and costs of IRDs that are borne outside of the healthcare system are not captured in most Health Technology Assessments (HTA), making it difficult to assess the true cost of these diseases through many national health assessment processes.

Launching the report at EURETINA 2019 in Paris, France, Director of Stakeholder Engagement at Retina International Dr Orla Galvin said ‘With improvements in genetic diagnosis and with novel therapies progressing through clinical trials, IRD patient registries should be developed. This study highlights the enormous burden of care for both the individuals vision impairment and their families. In both the RoI and the UK the highest costs incurred due to IRDs were attributed to well-being and loss of productivity, yet those affected by IRD do not regularly engage with health care providers. While this is no surprise to our community the data allows us to demonstrate clearly that the measurements used to assess the burden of vision loss need urgent review.”

ENDS

For further information on IRD COUNTS Contact: orla.galvin@retina-international.org

**Methodology**

The socioeconomic burden of these IRDs in the RoI and UK was estimated using a cost of illness methodology applying a prevalence approach (Larg & Moss 2011). The analysis was based on a targeted literature review and primary data collection**.**

**About IRD COUNTS**

IRD COUNTS is a patient led initiative and is made up of F. Hoffmann La Roche, Fighting Blindness Ireland, MeiraGTx, Novartis UK Ltd, ProQR, Retina UK, Thomas Pocklington Trust. All partners were equal funders of the project. This project was initiated by Retina UK.

IRD COUNTS is managed by Retina International.