**EURETINA, Paris, September 5th: The £523 Million cost of Inherited Retinal Dystrophies (IRDs) in the United Kingdom and the €49.5 Million cost of IRDs in the Republic of Ireland is largely borne by patients and their families. The IRD COUNTS study highlights for the United Kingdom a £196.1 Million cost of wellbeing, and £114.1 Million cost due to reduced involvement in the work force; and to the Republic of Ireland a €16 Million cost of wellbeing and €9.4 Million cost due to reduced involvement in the work force due to these conditions. Importantly, the cost of these diseases is not appropriately captured by current ways of assessing such disease needs, and, therefore services, treatments and research into IRDs are vulnerable to being underfunded.**

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

Despite the realities of life with an IRD being felt every day by patients and those who support them, the effects of IRDs on national and global levels are not documented. Lack of information in this area is a majoring stumbling block for developing and getting access to clinical services and treatments, as well as developing new treatments. There is an urgent need to gather stronger evidence on the impact of IRDs. This will support value-for-money proposals to regulatory bodies for recently approved therapies, and potentially new therapies progressing through clinical trials towards market. The information can support investment into critical genetic testing services for diagnosis, and into research that will aid progress in treatments for IRDs.

IRD COUNTS is a patient led multi-stakeholder consortium, managed by Retina International, focused on novel therapies and improved services for individuals with IRDs. IRD COUNTS engaged Deloitte Access Economics to do a ‘cost-of-illness’ study on IRDs in the Republic of Ireland (ROI) and the United Kingdom (UK), i.e. estimate the effect of IRDs on both everyday life and the economic impact of IRDs.

The pilot 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 the majority of IRD costs in the RoI (32.3%, €16 Million) and UK (37.5%, £196.1 Million). Productivity costs were the second highest cost burden due to IRDs in both the RoI and the UK, at €9.4 Million, and £114.1 Million respectively. Those affected by 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.

As well as the costs involved, the study investigated where those costs were borne. Overall, the cost to the health care systems in both countries was surprisingly low, at €2.2 Million (ROI) and £25.0 Million (UK) respectively. This means that most people in the study did not engage with the health care system very often, and when they did, it was likely to engage with social supports. However, the majority of costs associated with IRDs were disproportionately borne by the affected individuals and their families. While this is an unfair cost to the individuals, it is also a problem for recognizing the burden of these diseases on society. The current ways of measuring the costs of diseases, such as Health Technology Assessments (HTAs), do not capture these types of costs. This makes it difficult, if not impossible, for the true costs of these diseases to be assessed and therefore difficult to ensure that funding, in healthcare, services and research, is appropriately distributed based on true need for services and treatments.

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 wellbeing 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.”

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.

ENDS

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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.