Statement on Rare Disease Technology Review Group – October 2018

As part of the Irish National Plan for Rare Disease, published in 2014, the establishment of a Rare Disease Technology Review Group (RDTRG) was recommended. The group would assess Orphan Drugs that have received a negative Health Technology Assessment (HTA) by examining the impact of the specific conditions on patients and care givers, real world evidence along with scientific data. The Rare Disease Technology Review Group – RDTRG was formed to carry out this task in 20018.

The Rare Disease Task Force was established in 2008 to work towards the publication of the National Plan and is made up of the MRCG, IPPOSI and Rare Disease Ireland. The Task Force has long advocated that two patients and one alternative should sit on the RDTRG. This was approved by the Minister for Health, Mr. Simon Harris TD in 2018.

The Rare Disease Task Force held an election of its members and Avril Daly (Retina International and Rare Disease Ireland), Anne Marie O'Dowd (Cystinosis Ireland and IPPOSI) were elected to represent the patient perspective with Derick Mitchell (IPPOSI) as an alternate.

The RDTRG does not have the authority to approves drugs but will make recommendation based on the impact of disease, real world evidence and scientific data to the HSE's Drugs Committee with whom the final decision lies. The RDTRG has no remit to discuss price.

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