

# CCBS – LEGISLATIVE AFFAIRS

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27 April 2018 – 4 May 2018



Northern Ireland  
Assembly

The Northern Ireland Assembly was dissolved at 00:01 on Thursday 26 January 2017.



Wednesday 2 May 2018

Department of Finance

Paul Murphy asked the Minister for Finance if his Department is undertaking a review of the vehicle registration tax following recent European Court of Justice rulings; and if he will make a statement on the matter.

**Paschal Donohoe:** I believe the Deputy is referring to the CJEU judgment on Case C-552/15, Commission v Ireland (VRT on Cross-Border Leased Vehicles). Officials from my Department and Revenue are currently developing a proposal to implement the ruling of the Court, which is only concerned with the method of applying VRT charging in respect of leased or hired vehicles, imported from a Member State of the EU, and which are intended to be in the State for a limited and pre-determined period of time.

It is intended that legislative provisions which implement the Court ruling will be brought forward in Finance Bill 2018.

Source: <https://www.kildarestreet.com/wrans/?id=2018-05-02a.159&s=cross-border+2018-04-27..2018-05-04#g161.r>

**Thursday 3 May 2018**

**Department of Health**

Bernard Durkan asked the Minister for Health his plans for the implementation of the recommendations of the report on rare diseases; the parts of the recommendations already implemented or pending; the timeline for the implementation of the report in full; and if he will make a statement on the matter.

**Simon Harris:** In 2017 the Department published a progress report on the National Rare Disease Plan and this is available on the Department's website under 'Publications'. An update is also provided on all 48 recommendations of the Plan and on progress to date.

Establishment of a National Clinical Programme for Rare Diseases was one of the principal recommendations in the Plan. The Programme is responsible for assisting with mapping and developing care pathways for rare diseases; facilitating timely access to centres of expertise-nationally and internationally; and developing care pathways with European Reference Centres for those ultra-rare disorders where there may not be sufficient expertise in Ireland.

In line with the National Rare Diseases Plan, the National Clinical Programme for Rare Diseases and the Department of Health, encouraged designated centres of expertise in Ireland to apply for membership of European Reference Networks (ERNs) during the first round of calls from the European Commission for participation in European Reference Networks. Three of these centres are now represented on ERN network.

Membership of ERNs will bring opportunities for engaging in research relating to Rare Diseases in keeping with the National Rare Diseases Plan. Further centres are expected to apply for membership or affiliated membership of ERNs when the next call takes place in early 2018.

The establishment of a National Rare Disease Office (NRDO) was a key recommendation of the Rare Disease plan. The office provides current and reliable information about rare diseases to the general public, health care professionals, researchers and policy makers. The National Rare Diseases Office is responsible for updating Orphanet Ireland. Orphanet is the international rare disease reference and information portal funded by the EU. The office also manages the National Rare Diseases Information Line (a Freephone service) and provides online information about rare diseases on their website.

A number of recommendations about access to appropriate drugs and technologies were contained in the plan. One chief recommendation in this regard refers to the [HSE](#) developing a Working Group to bring forward appropriate decision criteria for the reimbursement of orphan medicines and technologies; and that the approach should include an assessment system similar to that for cancer therapies established under the National Cancer Control Programme. The [HSE](#) Acute Hospitals Division has developed the terms of reference, required membership and reporting relationship for this committee. A Chairperson has now been identified and the Group met in March 2018 to start

the process of identifying interested stakeholders and considering the remit of the Committee in relation to the assessment of drugs for rare diseases.

One of the recommendations of the National Plan for Rare Diseases was that the Health Identifiers Bill and the Health & Patient Safety Bill be published. The former was published in 2013 and enacted in 2014. The Individual Health Identifier part of the project is now being implemented by the [HSE](#). A revised and much expanded General Scheme of a Health Information and Patient Safety Bill was approved by the government in November 2015 and published on the Department's website.

Two recommendations referred to training in rare diseases for healthcare professionals. The Department of Health has contacted formally the various healthcare representative and professional bodies about implementing these recommendations. The National Rare Diseases Office developed eLearning modules for healthcare professionals. These modules are available on [HSE](#) website.

The issue of rare diseases and of the creation of an all-island patient register has been raised in the context of on-going discussions at North-South meetings. It is also anticipated that the Model of Care for Rare Diseases will set out recommendations for rare disease registries. This model of care is in development by the National Clinical Programme for Rare Diseases. At the EU level, the Joint Research Centre is developing a joint European Platform on Rare Disease Registration which will promote EU level standards for data collection and contribute to the development of rare disease registries across the EU.

The Plan also recommended that an Oversight Implementation Group of relevant stakeholders, including patients' groups, be established to oversee and monitor implementation of the plan's recommendations. This group was established by the Department of Health in 2015 and it has met on a number of occasions.

The National Rare Disease Plan continues to be implemented. The Department will consider the matter of a further plan as part of its Work Programme for 2018.

**Source:** <https://www.kildarestreet.com/wrans/?id=2018-05-03a.373&s=all-island+2018-04-27..2018-05-04#g375.r>