

CCBS – LEGISLATIVE AFFAIRS

1 December 2017 – 8 December 2017



Northern Ireland
Assembly

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



Tuesday 5 December 2017

Department of Agriculture, Food and the Marine

Brendan Smith asked the Minister for Agriculture, Food and the Marine the outcome of discussions he has had on the need to protect the progress made in the development of an all-island animal health plan; and if he will make a statement on the matter.

Michael Creed: There is ongoing, close co-operation between my Department and the Department of Agriculture, Environment and Rural Affairs in Northern Ireland, including through dedicated working groups established as part of the All-Island Animal Health and Welfare Strategy Action Plan by the North/South Ministerial Council. The working groups focus on critical issues such as disease control, animal identification and movement, cross-border communication, data sharing and the development of joint initiatives on animal welfare.

In October 2016 I chaired the most recent meeting of the North South Ministerial Council on agriculture. Together with Michelle McIlveen, then Minister for Agriculture, Environment and Rural Affairs, we welcomed the continuing work on the delivery of the Action Plan and, in the context of Brexit, looked forward to the continuation of practical and effective co-operation on animal health

and welfare, and disease control in both jurisdictions, in order that the health and welfare of livestock is maintained at the highest level.

Since December 2016 I have hosted a number of all-island civic dialogue events to discuss the implications of Brexit across the agrifood sector. These events provide important opportunities to engage directly in detail with stakeholders on the implications of Brexit and the potential responses that will be required as the negotiations unfold. The need to maintain an all-island approach to animal health/disease issues has been consistently highlighted during these discussions.

Source: <https://www.kildarestreet.com/wrans/?id=2017-12-05a.1057&s=cross-border+2017-12-01..2017-12-08#g1059.r>

Wednesday 6 December 2017

Department of Education and Skills

Brendan Smith asked the Minister for Education and Skills his plans to increase co-operation on a North-South basis in the further and higher education sectors.

Richard Bruton: A major objective of my Department is to contribute, in the context of the Good Friday Agreement, to the development of North-South co-operation and common action in the field of education.

North-South Co-operation is a priority activity identified in the Programme for Government. In this context, the strengthening and deepening of co-operation in education to achieve effective and efficient delivery of educational services for the benefit of all the people of this island remains a primary goal.

Work to date has included developing, within the framework of the North-South Ministerial Council, common policies in the designated areas of special education needs, educational underachievement, teacher mobility and school, youth and teacher exchanges.

Departments North and South have also been mandated to explore the potential for further areas of co-operation in education not within the existing NSMC framework. To that end there has been significant engagement and cooperation at Ministerial and official levels on higher education and skills issues in recent years covering higher and further education strategies and policies; legislative and institutional reform; funding of higher and further education; access/student mobility issues; cross-border student flows; research; and possible collaboration on EU funding programmes.

At institutional level, there is a broad range of cross-border collaboration particularly in research and innovation, which has been supported by EU funding programmes and national research funding programmes in Ireland. I will work to support the continuation of this valuable collaboration.

A key challenge for future North-South engagement will be how we manage the impacts of Brexit on our respective education systems in such areas as cross-border access to education; teacher and academic mobility and future collaboration on the island in research and innovation programmes.

In this context consultation is fundamental to my approach and I had already met and discussed these issues with the then Northern Ireland Minister for Education and the UK Secretary of State for Education. In addition my Department met with UK and Northern Ireland officials on a bi-lateral basis earlier this year and ongoing contacts are being maintained with NI and UK officials.

It is my aspiration that, with an eventual agreement in Northern Ireland on the restoration of the power-sharing executive, we can regain the momentum on North-South cooperation in higher and further education.

Source: <https://www.kildarestreet.com/wrans/?id=2017-12-06a.74&s=cross-border+2017-12-01..2017-12-08>

Tuesday 5 December 2017

Department of Health

Kate O'Connell asked the Minister for Health the status of the rare disease programme 2014 to 2018; and the details of the expected conclusion of same in 2018.

Simon Harris: It provides an update on all 48 recommendations as outlined in the Plan and progress to date.

One of the principal recommendations in the Plan was the establishment of a National Clinical Programme for Rare Diseases which 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 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) featured prominently in the recommendations 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 .

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 it is expected that the Group will convene in the near future.

The national plan for rare diseases recommended 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:

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The issue of rare diseases and of the creation of an all-island patient register has been raised in the context of ongoing 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.

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

Source <https://www.kildarestreet.com/search/?s=All-island+2017-12-01..2017-12-08>