



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

Oifig an Cheannaire Oibríochtaí,  
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,  
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4<sup>th</sup> May 2021

Deputy Bernard Durkan,  
Dail Eireann,  
Leinster House,  
Kildare Street,  
Dublin 2.  
e-mail: [bernard.durkan@oireachtas.ie](mailto:bernard.durkan@oireachtas.ie)

Dear Deputy Durkan,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary questions, which were submitted to this department for response.

**PQ 19741/21**

*To ask the Minister for Health when the report on Prader-Willi syndrome will be published; the extent to which matters arising are in hand with a view to meeting the concerns of families affected by this particular condition; and if he will make a statement on the matter.*

**PQ 19742/21**

*To ask the Minister for Health the progress to date on the provision of a respite centre for persons affected by Prader-Willi syndrome; if budgetary provision is adequate to meet this request; and if he will make a statement on the matter.*

**HSE Response**

The HSE acknowledges the work of the Prader Willi Syndrome Association of Ireland in raising awareness and understanding of PWS and the needs of persons with this syndrome. The Association provides information services, including seminars and conferences and promotes best practice standards of care for persons with PWS.

The HSE provides funding for the position of Development Officer for Prader Willi Syndrome Association and will be allocating €75,590.5 to PWSAI in 2021 and beyond as a grant aid agreement.

The position of the Development Officer at PWSAI will allow the Association to increase capacity to spread awareness of the unique nature of PWS and assist with the development of specific services tailored to the condition. Having successfully bid for the IPWSO International Conference in 2022, PWSAI want to plan and deliver a Conference that highlights best practice in caring for PWS through collaboration with all relevant stakeholders. Other objectives of the role includes:

- Increase the knowledge and understanding of PWS with relevant stakeholders across a life time of care.
- Publication and promotion of the recommendations agreed in the joint work group report between HSE and PWSAI.
- Increase the supports available to families with PWS across a life time of care.
- Liaise with and support families

- Understand the Impact on siblings in a family with a member that has PWS.
- Develop a clinical pathway for individuals with PWS within a centre of expertise where a seamless transition of care is provided from birth through childhood, adolescence and adulthood.
- Develop PWS specific training material tailored for Clinicians, Medical Professionals, Educators, Carers, Service Providers etc

In addition the HSE provides funding to Rehab Group to run a dedicated community residential service in Dublin set up in 2003, which offers residential care to 5 young adults with PWS.

### **Draft joint HSE/PWSAI report**

The HSE, in collaboration with the Prader-Willi Syndrome Association of Ireland (PWSAI), have developed a draft report on Prader-Willi Syndrome (PWS). As agreed at a meeting on February 4th 2021 hosted by Minister Rabbitte (Minister of State for Disability) and Minister Butler (Minister of State for Mental Health and Older People), and attended by PWSAI, this draft report is now being reviewed by a wider stakeholder task group to identify what aspects of this report may be implementable, and the most expedient means of implementing same. This will include consideration of the need for, and the feasibility of, a respite centre for persons with PWS. This process is being overseen by the National Clinical Programme for People with Disability (NCPDP) by establishing a new Model of Service for PWS. The incorporation of reports into a Model of Service is the mechanism used in disability services to ensure that appropriate recommendations are actioned either within existing structures, or through the development of new structures. In the case of the proposed Model of Service for PWS, it is likely that some additional funding will be required but the amount is yet to be determined. The NCPDP are working with PWSAI to develop and then publish the Model of Service .

Yours sincerely,



**Dr. Cathal Morgan,  
Head of Operations - Disability Services,  
Community Operations**