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Deputy Caoimhghín Ó Caoláin,
Dáil Eireann,
Leinster House,
Kildare Street,
Dublin 2.

PQ 26739/19

To ask the Minister for Health the full range of State supports provided to persons with Friederichs's ataxia; the annual resource support provided to an organisation (details supplied); the supports or level of involvement by Ireland in research towards identifying a treatment or cure for the disease; and if he will make a statement on the matter.

Details supplied: the Ataxia Foundation Ireland

-Caoimhghín Ó Caoláin

Dear Deputy Ó'Caoláin,

The Health Service Executive (HSE) has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted to the Minister for response.

Ataxias are a group of rare neurological disorders with a variety of underlying causes characterised by slowly progressive combination of gait instability, limb incoordination, slurred speech and nystagmus.

The National Ataxia Clinic (NAC) in Tallaght University Hospital (TUH) is a multidisciplinary clinic, led by two consultant Neurologists and is the designated centre of expertise in Ireland. An ataxia research registrar and an ataxia nurse specialist are also employed and were previously funded by Ataxia Ireland and are now funded by pharma-based grants. Referrals are accepted from GPs or specialists within the Republic of Ireland. 40% of referrals are second specialist opinion and come from other neurology centres in Ireland. Access to a specialised centre such as the NAC at TUH for comprehensive assessment increases success rates for number of areas including: establishing a diagnosis and appropriate genetic evaluation; developing expert guidance for future management and also allows for focused clinical research.

A combined Ataxia clinic and cardiology clinic with a cardiologist with a special interest in inherited cardiac disorders is offered at NAC, allowing for same day Neurological and Cardiac assessment for patients predominantly with Friedreich's Ataxia. Patients attending the clinic have access to Allied Health Care Professionals (AHCPs) including Physiotherapy, Occupational Therapy, Speech and Language Therapy, Neuropsychology, Dietetics and Medical Social Work. Access to AHCP's services can also be accessed through local primary care teams.

The Raymond P Murphy Neurology Assessment and Research Unit (NARU) opened in 2016 at TUH to provide a dedicated space for the evaluation, education and research of patients with chronic neurological diseases. Patients with inherited ataxia are being clinically assessed in the NARU as part of the rapid access outside the Ataxia Clinic hours. In addition, individuals with ataxia and their family members attended the NARU for further genetic testing.

The team at the NAC have been involved in a wide breath of research on a local, national and international research projects with many specific to Friedreich's Ataxia over the past number of years and endeavour to continue to engage in research pertaining to Ataxia's causation and treatment options.

In relation to the Ataxia Foundation Ireland, this office is not aware of any funding being provided to this organisation from the HSE. We have however provided funding to other organisations which provide support for people living with Ataxia in Ireland, namely Ataxia Ireland who received €46,194 in S39 Grants in 2018 and a further 9,258 in Lottery grant.

I trust this information is of assistance to you.

Yours sincerely,



David Walsh,
National Director,
Community Operations