

## PRESS RELEASE

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### **Lack of Services Place Severe Strain on those living with Prader-Willi Syndrome**

- *First National Survey on the needs of people with PWS Released* -

There needs to be greater awareness of a very complex, unique condition, and recognition of the cumulative effect of multiple needs on families. That's according to the Prader Willi Syndrome Association Ireland, who today (09.03.2017) launched the first national survey on the needs of people with PWS and their families. The survey was launched by **Minister for Health Simon Harris TD** at an event in Buswells Hotel, Dublin 2.

PWS is a complex genetic disorder that typically causes low muscle tone, restricted growth, learning difficulties, problem behaviours, and a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity. PWS is also associated with an increased risk for numerous other medical and comorbid psychiatric problems including scoliosis, hip dysplasia, seizures, gastrointestinal and skin problems, depression, anxiety and psychosis. There is currently no cure for PWS and because of the complexity of the condition care is required by a range of medical specialists from different disciplines.

Approximately 100 people in Ireland are living with PWS. The survey highlights the unique needs of people with PWS and the challenges faced by their families when caring for them. The hallmark characteristic of PWS is hyperphagia, which refers to an insatiable appetite or drive to eat. Hyperphagia typically leads to people with PWS needing to have all access to food restricted at all times - for example, by means of locked kitchens, and restricted or no access to money.

Launching the report, Minister for Health, Simon Harris TD, said: "I commend all the efforts of the Prader Willi Syndrome Association Ireland in raising awareness and understanding of PWS. The Charity does important work in identifying and furthering the needs of people with this syndrome and I am delighted to lend my support to this morning's event."

Anthony Carr, Chairperson of PWSAI commented on the significance of the report saying: "This report clearly highlights the unique, complex and changing nature of PWS over the lifetime of the individual. It also highlights that due to a lack of understanding of the nature of PWS by our state bodies, families are left isolated while seeking services, particularly when their loved-one with PWS is transitioning into adulthood.

"The lack of available supports is a considerable burden on the carers and families of people with PWS both financially and emotionally. PWSAI commissioned this report to provide a baseline to inform our advocacy for improved services at a national and local level. With five to six babies born with PWS every year, this report can be used as a framework for service provision. We will use the report to ensure people living with PWS, their families and their carers are supported in all aspects of care, education and well-being."

#### **Key Findings**

Key findings from the report include:

- People with PWS face significant challenging behaviours and mental health problems that are most severe from adolescence on. 22 per cent of adolescents were reported to have a specific mental health problem; this figure rose to 60 per cent for adults.

- The results showed that a majority of people reported on in the study have mild intellectual disability.
- 87% of babies born with PWS are admitted to ICU (average stay of 26 days).
- More than 40 per cent of adults with PWS require assistance with everyday tasks such as showering, brushing their teeth and using the toilet.
- 93 per cent of adults living with PWS require help with managing healthcare needs, such as taking medication.
- None of the adults with PWS included in the survey are living independently.

Only six per cent of those caring for young children (5-12 years) report to have access to respite care. This increases to 40 per cent in adolescents but decreased to 25 per cent for adults affected.

The cumulative effect of medical needs, care needs, challenging behaviours and mental health problems, intellectual disability, and hyperphagia were shown in this research to present very significant difficulties for families.

### **Strain on Families and Carers**

People with PWS often require round the-the-clock supervision and care. As well as showing the many medical, psychiatric and behavioural challenges faced by people with PWS, the research also highlighted that PWS takes a heavy financial, physical and emotional toll on families and has a negative impact on sibling mental health and family relationships. The emotional and day-to-day stress is considerable and negatively impacts the quality of life among 70-80 per cent of respondents to the survey.

Speaking at the launch, Jane Cox, parent of 18-year old Laura who has PWS, said: “Living with PWS has been a huge strain on our lives. Laura’s psychological needs are now such that my husband and I can no longer holiday together, or even go out for dinner as a family. I’ve had to give up my job as a teacher, which I loved, to become Laura’s full-time carer. We are the living embodiment of the survey statistic that 75% of carers of adults with PWS living at home have no access to respite care. The publication of this survey validates our everyday struggles, and is a very important milestone for us. We hope it will go some way towards putting more supports in place for people with PWS and their families, and ensuring that Laura will always have the assistance she needs as my husband and I grow older.”

### **Recommendations**

PWSAI outlined a number of recommendations in the report, including:

- The development of PWS-specific residential accommodation for adults living with PWS. The research undertaken showed that 16 people with PWS will require accommodation in the next five years, which equates to three new PWS-specific houses.
- PWS-specific respite services, with a clear need for overnight respite identified in the report.
- Access to consultant psychiatrists who specialise in intellectual disability and rare disorders, including PWS.

The survey report ‘A Population-Based Profile of Prader-Willi Syndrome in Ireland’ is a collaboration between the Prader Willi Syndrome Association Ireland (PWSAI), Trinity College Dublin and Tallaght Hospital, and was authored by Professor Louise Gallagher. The report is available to download at [www.pwsai.ie](http://www.pwsai.ie).

**ENDS**

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**Notes to Editor:**

The survey report is available to download from [www.pwsai.ie](http://www.pwsai.ie).

Jackie McHugh and Jane Cox, parents of people with PWS, are available for interview / comment.

**About PWSAI:** The Prader Willi Syndrome Association Ireland (PWSAI) is an organisation founded by parents in the late 1980s as a support group for individuals with PWS and their families in Ireland. Our mission is to raise awareness and understanding of PWS and to improve the choice and quality of care, education and support for persons living with PWS. For more information please visit [www.pwsai.ie](http://www.pwsai.ie).