

## What is Prader-Willi Syndrome?

**Prader-Willi Syndrome** is a rare, complex genetic disorder that is most recognised by a chronic feeling of hunger that can lead to excessive eating and subsequent life threatening obesity.

### Other Symptoms include:

- Low Muscle Tone
- Autistic Features
- Behavioural Problems
- Scoliosis
- Sleep Apnea
- Cognitive Disabilities

**The Galway Cycle 2014** will fund the Prader Willi Syndrome Association Ireland (PWSAI) Education, Training & Research Initiative to help increase knowledge and awareness of Prader-Willi Syndrome within Ireland.

The Galway Cycle 2014 logo will be included in information packs and training videos.

## PWSAI EDUCATION, TRAINING AND RESEARCH INITIATIVE

<b>Information Packs</b>	A series of information packs about Prader-Willi Syndrome. Packs will be distributed to families (including extended family), GPs, hospitals and other medical professionals working with children with Prader-Willi Syndrome. Packs will include: New Parents, Starting School and The Teenage Years.
<b>Training Videos</b>	A set of training videos. We have already secured agreement from a range of international experts on Prader-Willi Syndrome that they would make presentations to camera about specific aspects of the syndrome.
<b>Conferences</b>	One or more conferences featuring international experts and focusing on issues of particular relevance to children. A conference is planned for September 2014 with international speakers from the International Prader-Willi Syndrome Organisation. (IPWSO)
<b>Bursary Scheme</b>	A bursary scheme to enable people working or living with children with Prader-Willi Syndrome to pursue relevant training and share knowledge.
<b>Research Fund</b>	A research fund to stimulate research into PWS and the needs of children with PWS and their families in Ireland. One proposed project is a baseline survey of people with PWS and their families in Ireland.

**If you can't find the right information, we've found it for you!**

- **PWSAI GC14 video**
- [www.youtube.com/watch?v=OR0L4wefV4&app=desktop](http://www.youtube.com/watch?v=OR0L4wefV4&app=desktop)
- **Stories from three Irish families**
- [www.irishexaminer.com/ireland/health/this-is-our-life-now-and-not-in-a-bad-way-177762.html](http://www.irishexaminer.com/ireland/health/this-is-our-life-now-and-not-in-a-bad-way-177762.html)
- **Story from Maynooth family**
- [www.leinsterleader.ie/news/features/they-told-us-not-to-google-it-maynooth-couple-tell-their-story-1-5725693](http://www.leinsterleader.ie/news/features/they-told-us-not-to-google-it-maynooth-couple-tell-their-story-1-5725693)
- **Irish mother on the everyday issues of PWS**
- [ipwso.blogspot.ie/2013/10/01\\_archive.html](http://ipwso.blogspot.ie/2013/10/01_archive.html)
- [ipwso.blogspot.ie/2013/12/skepticism-and-ignorance\\_15.html](http://ipwso.blogspot.ie/2013/12/skepticism-and-ignorance_15.html)
- [ipwso.blogspot.ie/2014/01/a-kitchen-with-no-food-in-it.html](http://ipwso.blogspot.ie/2014/01/a-kitchen-with-no-food-in-it.html)
- **You know you're a PWS parent if...**
- [divingintothewaves.blogspot.ie/2010/06/you-know-youre-pws-momdad-if.html](http://divingintothewaves.blogspot.ie/2010/06/you-know-youre-pws-momdad-if.html)
- **Ireland AM coverage**
- [www.youtube.com/watch?v=FRhbmKwqLHE&desktop\\_uri=%2Fwatch%3Fv%3DFRhbmKwqLHE&app=desktop](http://www.youtube.com/watch?v=FRhbmKwqLHE&desktop_uri=%2Fwatch%3Fv%3DFRhbmKwqLHE&app=desktop)
- **A powerful multimedia piece on PWS**
- [vimeo.com/5717103](http://vimeo.com/5717103)

**For more information on Prader-Willi Syndrome, please visit [www.pwsai.ie](http://www.pwsai.ie)**