



Down Syndrome Ireland

Down Syndrome Regression Disorder (DSRD)



What is Down Syndrome Regression Disorder?

Down Syndrome Regression Disorder (DSRD) is a sudden and significant loss of skills in adolescents and young adults with Down syndrome.

This regression happens suddenly over a short period of time, it could be days, weeks or months, rather than years. DSRD is rare, and seems to affect men and women equally. DSRD might look like late onset Autism or early onset Alzheimer's disease, however the rapid regression and the age of onset suggest a different cause.

Regression significantly reduces the independence and quality of life of the person with Down syndrome and deeply impacts the entire family.

While any loss of skills is distressing and needs investigating, DSRD involves a loss of skills over multiple areas.

NB: Changes that persist longer than 1–2 weeks and impact daily function should always be investigated.

Things families have noticed include:

- Changes in communication: loss of speech or very quiet whispery speech, reduced sentence structure or use of words, repetitive speech, echoing, reduced facial expression, loss of interest in communicating.
- Changes in eating and drinking habits.
- Disturbed sleep patterns.
- Needing more help with showering, dressing, going to the toilet or moving around, sometimes to the point of complete lack of self-care abilities and incontinence.

- Social withdrawal: loss of interest in people or activities previously enjoyed, avoiding interaction, reduced eye contact.
- New onset (or increased severity) of anxiety, depression, irritability or aggression.
- Movement changes like slowness, repeated movements, freezing, or difficulty starting a movement.
- Psychiatric changes like hallucinations, confusion, laughing or crying which is unrelated to events, or disorganised thoughts.

DSI have been engaging with families, and the symptoms described above come from our survey, which remains open.

The recognition of DSRD as a specific condition is relatively recent, and new information on presentation, causes and treatments is emerging. Our survey is intended to gather information and share experiences about the impact on families in Ireland.

If you are experiencing regression in your family, you are welcome to complete the survey, which is anonymous. Please do not share identifying information. [Click here](#) to access the survey.

Next Steps:

There is no one-size-fits-all treatment for DSRD, and every person will need an individualised treatment plan, but the first step is to note the areas of concern and discuss the possibility of Down Syndrome Regression Disorder with your GP.

As there are many social and medical factors that can impact on the wellbeing of people with Down syndrome, it is important to investigate health issues and make note of life changes which may have triggered cognitive, functional or behavioural change. This is essential, because if regression is found to be linked to a medical condition, treating the condition may reduce the symptoms of regression.

Information on Diagnostic Workup for GPs

Your GP can begin initial screening with physical examination, blood tests, and referral to relevant specialists as needed. Any health concerns which may be contributing to the regression should be investigated and treated.

There is a summary of suggested checks on [Page 6](#) which might be helpful to take with you to your GP.

NB: Our survey suggests that the most common referral in Ireland is to Psychology or Psychiatric services, however research would indicate that medical investigations, particularly neurology, should be prioritised initially.

Resources

Online Monthly Regression Support Meeting

If you are a parent or caregiver of someone experiencing regression? Connect with others who understand. Our monthly support meetings offer a safe, compassionate space to share experiences and advice. To access the group, [register here](#).

Self-Assessment (for Parents/Carers)

[This checklist](#) from Down Syndrome Australia is very useful.

Webinars:

- [This webinar](#) features Dr Jonathon Santoro and Prof Colin Doherty talking to families and professionals in Ireland in August 2026.
- [This webinar](#) features Dr Jonathan Santoro talking to families and professionals in Ireland on 29th of May 2025.
- [This webinar](#) is aimed at families and professionals, looking at various conditions which can cause a decline in skills including DSRD, and is presented by Dr Brian Chicoine.
- [This webinar](#) features Dr Brian Chicoine talking to the Down Syndrome Association in the UK in July 2025.

Q&A:

- [Here is a Q&A](#) from families with Dr Jonathon Santoro and Prof Colin Doherty.

Down Syndrome Regression Disorder Comparative Study

There was a recent study focusing on the effectiveness of Lorazepam or IVIg Versus no Treatment for DSRD. [You can read it here.](#)

Further reading and research:

- Chicoine and McGuire [1] have a chapter on regression in the book 'Mental Wellness in adults with Down syndrome' (Chapter 27, pages 427-440) with lots of useful information which is worth reading, and is available as a free download [here](#).
- In 2022, an international team of 25 medical professionals developed a global consensus on the nomenclature, assessment, and diagnostic testing for DSRD. [Click here to read.](#)
- There are ongoing treatment trials happening in the USA, and subsequent research on treatment options has been published:
 - [Jonathan D Santoro and others, 'Immunotherapy Responsiveness and Risk of Relapse in Down Syndrome Regression Disorder' \(2023\) 13 Translational Psychiatry 276.](#)
 - [Jonathan D Santoro and others, 'Down Syndrome Regression Disorder: Updates and Therapeutic Advances' \(2023\) 36 Current Opinion in Psychiatry 96.](#)

Sharing the Journey of Regression

Down Syndrome Ireland's Gina Grant hosts a monthly webinar. This group is for families supporting a loved one with with symptoms of Regression, it is a safe and understanding space for families - [Click her for the zoom link.](#)

Down Syndrome Regression Disorder

Medical Checklist

Bring this with you to the GP.

Initial blood tests recommended for all (Santoro et al, 2022):

☐ Ammonia	☐ Lipid panel HbA1c	☐ Anti-thyroglobulin antibodies
☐ FBC	☐ B12 Level	☐ Anti-thyroid stimulating hormone receptor
☐ CMP	☐ Vitamin D 25-OH level	☐ ANA
☐ ESR	☐ TSH w/reflex T4	☐ Coeliac serology or panel
☐ CRP	☐ TPO antibodies	☐ Cell based auto-immune encephalitis panel

If no clear cause is identified, refer to specialists, usually:

- Neurology
- Respiratory medicine (Sleep apnoea is common)
- Psychiatry
- Psychology

Any health concerns which may be contributing to changes in wellbeing or social interaction should also be investigated. For example, consider:

- Cardiology
- Audiology
- Endocrinology



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Published by Down Syndrome Ireland
in October 2025.

Updated August 2026.