

BRITISH PAEDIATRIC SURVEILLANCE UNIT Reporting Instructions & Case Definitions – MAY 2025

When reporting a case **PLEASE** keep details of patients for reference.

IMPORTANT NOTICE
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Please inform the office of retirements or circumstances that will affect your ability to return the orange card. Complete the report card by ticking "nothing to report" or indicating the number of cases of the listed conditions seen in the month specified.
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1. Rapid-onset obesity with hypoventilation, hypothalamic dysfunction and autonomic dysregulation (ROHHAD)

Reporting instructions:

Please **report all existing and new cases** you have seen in the last month fulfilling this case definition of ROHHAD (in the UK and Republic of Ireland) not previously notified.

Case definition for ROHHAD:

Please report any patients under the age of 16 years with:

- i) Rapid onset of obesity in childhood after 12 months of age in a previously healthy child
 - a. with evidence of crossing three major centile lines for weight within a 12-month period (e.g. 9th to 75th centile)
 - b. or family photographic evidence of highly significant weight gain in 12 months, in cases with no baseline weight measurement.

AND

- ii) Sleep disordered breathing requiring overnight respiratory support

Exclusion, any of:

- 1. Evidence of structural abnormality of hypothalamic-pituitary axis on MRI
- 2. Congenital structural brain abnormality e.g., septo-optic dysplasia
- 3. Acquired brain injury e.g., craniopharyngioma
- 4. Other cause identified for obesity e.g., Prader Willi syndrome, monogenic obesity
- 5. PHOX2B variant associated with congenital central hypoventilation syndrome