

# BRITISH PAEDIATRIC SURVEILLANCE UNIT

## Reporting Instructions & Case Definitions – MARCH 2022

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

### IMPORTANT NOTICE

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.

#### 1. Progressive intellectual & neurological deterioration (Excluding Republic of Ireland)

**Case Definition:** Any child under 16 years of age at onset of symptoms who fulfils **ALL** of the following three criteria:

- Progressive deterioration for more than three months with
- Loss of already attained intellectual/developmental abilities and
- Development of abnormal neurological signs.

**Excluding:** Static intellectual loss e.g. after encephalitis, head injury or near drowning.

**Including:** Children who meet the case definition even if specific neurological diagnoses have been made.

- Metabolic disorders leading to neurological deterioration.
- Seizure disorders if associated with **progressive** deterioration.
- Children that have been diagnosed as having neurodegenerative conditions but not yet developed symptoms

**Reporting restricted to:** Cases seen in the last month but including those whose conditions began earlier (i.e. including 'old cases' of children in follow-up if seen in that month).

**Reporting Instructions:** Please report any child seen in the last month who meets the case definition, including those who have already been given a specific diagnosis.

#### 2. Congenital rubella

**Case Definition:** Any infant (live or still born) or child up to 16 years of age who, in the opinion of the notifying paediatrician, has suspected or confirmed congenital rubella with or without defects, based on history, clinical and/or laboratory findings. Please include "imported cases", including children born in the British Isles where the maternal infection occurred abroad, AND children who were born abroad.

**Reporting Instructions:** Please report any infant (live or still born) or child seen by you for the first time in the last month who meets the case definition, **REGARDLESS OF COUNTRY OF BIRTH.**

#### 3. Neonatal complications of coronavirus disease (COVID-19) (Excluding Republic of Ireland)

**Case definition:** Any baby or infant:

That has a diagnosis of COVID-19 made on a sample taken before 29 days of age and receives inpatient care for COVID-19 (this includes postnatal ward, neonatal unit, paediatric inpatient wards, PICU)

**Reporting instructions:** Please report any neonate that meets the case definition for neonatal complications of Coronavirus disease (COVID-19).

#### 4. Multi-system inflammatory syndrome, Kawasaki disease and toxic shock syndrome

**Case definition:** Any child aged <16 years **with 1 OR 2 OR 3** since March 2020 regardless of COVID-19 status:

1. Evidence of hyperinflammation:

- a. Fever >38 °C **AND**
- b. CRP >100 mg/L **AND**
- c. With one or more of the following:
  - i. Cardiac involvement (any one of the following)
    - myocarditis/pericarditis/valvulitis **OR**
    - coronary artery involvement (echo) **OR**
    - cardiac failure/arrest.
  - ii. Gastrointestinal involvement (any one of the following)
    - vomiting/diarrhoea **OR**
    - an acute abdomen **OR**
    - abnormal liver function (LFTs/clotting).
  - iii. Respiratory failure (requiring any one of the following)
    - high flow and humidified oxygen (HFHO) **OR**
    - CPAP **OR**

- ventilation.
  - iv. Raised Ferritin (>500) +/- Raised D-dimers (>2x upper limit of normal).
  - d. **AND** no pathogen (except SARS-CoV-2) or diagnosis (e.g. confirmed appendicitis).
2. Typical or atypical Kawasaki Disease.
  3. Typical or atypical Toxic Shock Syndrome.

**Reporting instructions:** Please report any child seen in the last month who meets the above case definition in the UK and the Republic of Ireland.

## 5. Glucocorticoid induced adrenal suppression

**Case definition:** Any patient under 16 years of age whose symptoms or signs\* partly or entirely reflect abnormally low adrenal cortisol production arising because of recent or ongoing glucocorticoid administration (adrenal suppression). The inadequate cortisol production may result in symptoms on a regular basis or be manifest acutely in association with a stressful event or illness.

*\* Signs/symptoms could include hypotension, shock, unexplained hypoglycaemia or hyponatraemia, seizure, lethargy, decreased level or loss of consciousness, anorexia, fatigue, myalgia, gastrointestinal symptoms (nausea, vomiting, abdominal pain) growth failure, death (Goldbloom et al. 2017).*

**Excluding:** Cases of primary adrenal failure arising because of intrinsic adrenal pathology such as autoimmune Addison's disease or secondary adrenal insufficiency in patients with pituitary hormone deficiency, including those with combined pituitary hormone deficiency and isolated ACTH deficiency who are normally on GC replacement. Also excluded are infants less than 6 months of age who were also born preterm (<37 weeks gestation).

**Reporting instructions:** Please report any child seen in the last month who meets the case definition seen in the UK or Republic of Ireland. If the diagnosis is awaiting confirmation; the child should still be reported.

## 6. Conservative care in end-stage kidney disease

**Case definition:** Any incident children aged less than 16 years who develops kidney failure, also known as 'end-stage kidney disease' (ESKD), during the study period for whom an active decision has been made in the child's best interests not to pursue long-term RRT\* and to instead manage the child's kidney disease conservatively (this decision may have been made before or after reaching ESKD).

*\* RRT refers to invasive treatments used to substitute the role of the kidneys and includes: Haemodialysis; haemodiafiltration; peritoneal dialysis; renal transplantation; continuous forms of RRT used on Paediatric Intensive Care Units such as continuous venovenous haemodialysis (CVVHD), continuous veno-venous haemodiafiltration (CVVHDF) and slow continuous ultrafiltration (SCUF).*

**Reporting instructions:** Please report any cases of children and young people <16 years of age who meets surveillance case definition seen in the last month in the UK or the Republic of Ireland.

Please report cases even if you think they may have been reported elsewhere.

## 7. Chronic recurrent multifocal osteomyelitis / chronic nonbacterial osteomyelitis (CRMO/CNO)

**Case definition:** Children and young people up to but not including the age of 16 years with a new diagnosis of possible CRMO/CNO, namely those who have the following features:

- The presence of localised bone pain, which could be single site or multiple sites

**AND**

- The presence of typical radiological findings on plain X-ray (examples include: lysis, sclerosis, cortical thickening or periosteal reaction) or on MRI (examples include: bone marrow oedema on fluid sensitive sequences, or periostitis (periosteal inflammation))

**AND**

- The treating clinician has determined that the clinical features are not explained by an alternative diagnosis, eg trauma, infection or neoplasm.

**Reporting instructions:** Please report children/young people up to the age of 16 years with new diagnosis of possible CRMO/CNO in the last month in the UK and Republic of Ireland.

## 8. Outcome of resuscitated term babies with no heart rate detected at 10 minutes of age

**Case definition:** Any baby who has been cared for in the last month for whom all three of the following conditions were met:

1. Gestational age 37 or more completed weeks of gestation
2. Cardiopulmonary resuscitation following delivery
3. No heart rate detected at 10 minutes of age.

**Reporting instructions:** Please report any cases of babies meeting the surveillance case definition whom you have seen in the last month in the UK or the Republic of Ireland.

## 9. Button battery ingestion, inhalation or insertion (excluding Scotland)

**Case definition:** Any presentation of any child under the age of 16 years who has ingested or aspirated a button battery of any description requiring hospital admission including those that were admitted for only observation (excluding Scotland).

**Reporting instructions:** Please report any child under 16 years of age who has a suspected or confirmed ingestion or inhalation of a button battery who has gone on to require admission, including those that were admitted for only observation (excluding Scotland).

## 10. Avoidant/Restrictive Food Intake Disorder (ARFID)

**Case definition:** Any child or adolescent aged 5 to 15 years with persistent restriction of quantity and/or range of food intake, associated with one or both of the following:

1. Nutritional deficiency that requires additional clinical investigation or treatment (e.g. anaemia, micronutrient deficiency, weight loss or poor growth, reliance on nutritional supplementation) that is not fully accounted for by poverty or neglect, cultural practice or an existing medical condition or another mental disorder\*
2. Interference with day-to-day functioning due to eating behaviour (e.g. unable to eat at school or with peers, needs to take preferred foods when out of home, extreme and frequent distress about eating).

Not explained by **ANY** of the following:

- a. Lack of available food (e.g. from poverty, famine or neglect)
- b. Culturally sanctioned practice (e.g. endorsed religious and cultural practice)
- c. Other known diagnosis:
  - e.g. Allergy to specific food group (e.g. dairy)
  - Gastrointestinal disorder
  - Constipation
  - Swallowing difficulties
  - Other eating disorder e.g. anorexia nervosa, bulimia nervosa
  - Other medical or psychiatric disorder that fully explains food restriction (not requiring additional clinical attention) e.g. depression, anxiety, OCD, malignancy, diabetes mellitus, inflammatory bowel disease, thyroid disease

*\*If eating disturbance occurs in the context of another condition/disorder, then in order to meet case definition for ARFID, the severity of eating disturbance should exceed that routinely associated with the particular condition/disorder - and warrant additional clinical attention.*

**Reporting instructions:** Please report any newly diagnosed cases of ARFID seen in the past month in children between the ages of 5 years and before the 15th birthday (17th birthday for CAPSS).

## 11. Neonatal stroke presenting/diagnosed in the first 90 days of life

**Case definition:** Neonatal stroke, of either arterial ischaemic, venous thrombosis or haemorrhagic in origin, suspected in any child from birth till 90 days of age, of any gestation. They must have:

Any neurological symptoms (including seizure, neurological deficit, lethargy, abnormal tone, poor feeding)

**AND either**

- 2a. Neuroimaging (such as MRI or CT) showing disruption or evidence of disruption of cerebral blood flow
- 2b. Neuropathologic studies showing disruption or evidence of disruption of cerebral blood flow

**Excluding:** Cases of germinal matrix haemorrhage/intraventricular haemorrhage or periventricular leukomalacia in preterm infants (defined as below 37 weeks of gestational age) or hypoxic ischaemic encephalopathy.

**Reporting instructions:** Please report any child seen in the last month who meets the case definition seen in the UK or Republic of Ireland.