

BRITISH PAEDIATRIC SURVEILLANCE UNIT

Reporting Instructions & Case Definitions – MARCH 2019

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. HIV infection and vertical HIV exposure

Case Definition: Any child under 16 years of age who has HIV infection (regardless of country of birth), **or** any child born to a woman known to have been diagnosed with HIV by the time of that child's birth (regardless of the child's infection status).

Reporting Instructions: Please report any child not previously reported to the BPSU who meets the case definition.

2. Progressive intellectual & neurological deterioration

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.

3. 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**.

4. Juvenile-onset systemic lupus erythematosus (JSLE)

Case definition: Any child / young person aged up to 18 years of age who:

1. Has a new, consultant diagnosis of suspected JSLE **AND**
2. Fulfils 2 or more ACR criteria* **AND** / OR has lupus nephritis on biopsy **AND**
3. Has no alternative diagnosis for relevant disease features

* A copy of the ACR criteria can be viewed at <http://www.rcpch.ac.uk/bpsu/lupus>

Reporting instructions: Please report any child / young person aged up to 18 years of age who meets the case definition in the UK and ROI.

5. Listeria infection in infants <90 days

Case definition: In young infants <90 days a microbiologically confirmed listeria sepsis or meningitis, or in babies < than 7 days old probable listeria sepsis or meningitis defined as Isolation or PCR confirmation of listeria from maternal cultures (Blood or CSF, placenta or genital tract) and/or isolation of listeria from surface swabs, meconium or nasogastric aspirate from baby and clinical signs of sepsis and treatment of the baby with at least 5 days of appropriate antibiotics, or clinical signs of meningitis and CSF pleocytosis (WCC ≥ 20 cells / mm³).

Reporting instructions: Please report any infant of 90 days of age or less with a clinical diagnosis of invasive listeria infection according to the treating clinician or with suspected listeria infection treated for at least 5 days with appropriate antibiotics in the UK and ROI.

6. Acute severe poisonings in children (ASPIC)

Case definition: Any accidental or unintentional poisoning in children <15 years resulting in:

1. death **AND/OR**
2. signs and symptoms defined as needing **ANY** of the below interventions

A. Further Monitoring	<ul style="list-style-type: none">• Continuous Oximetry PLUS Oxygen PLUS ECG monitoring• Arterial/CVP monitoring
B. Further airway and respiratory support	<ul style="list-style-type: none">• Invasive ventilation or• Non-invasive ventilation e.g. CPAP• Use of an adjunctive airway e.g. NPA• Nebulised adrenaline for airway obstruction,• Intravenous bronchodilators
C. Cardiovascular support	<ul style="list-style-type: none">• 40 mls/kg fluid resuscitation• >80 mls/kg fluid resuscitation over 24 hours• Inotropic/vasopressor treatment• Arrhythmia needing treatment or acute cardiac pacing
D. Neurological Support	<ul style="list-style-type: none">• GCS < 12 AND frequent GCS monitoring (1 hour or less)• Prolonged epileptic seizure requiring continuous IV infusions
E. Other support	<ul style="list-style-type: none">• Acute renal replacement (e.g. CVVH/HD/PD)• Plasma filtration or Exchange transfusion• Extracorporeal Liver Support (MARS) or Admission to a Paediatric Liver Unit• CPR in the last 24 hours

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

7. Fetal alcohol syndrome

Case definition: Any child < 16 years old newly diagnosed with FAS in the last month based on the presence of all three of the following clinical features:

1. **Facial features*:**
 - Smooth philtrum
 - Thin upper lip
 - Short palpebral fissures
2. **Poor growth:**
 - In utero < 10th centile for gestational age
 - Postnatal – FTT
3. **Structural or functional brain abnormality:**
 - Head circumference < 10th centile or microcephaly with increasing age
 - Abnormal brain scan
 - Developmental delay / learning difficulties
 - Abnormal neurological signs

*please refer to palpebral fissures and philtrum guide at www.rcpch.ac.uk/sites/default/files/2018-10/palpebral_fissures_and_philtrum.pdf

A history of maternal alcohol use during pregnancy is not required for reporting and cases may be reported if this is uncertain or unknown.

Reporting instructions: Please report any cases of babies or children under 16 years of age meeting the surveillance case definition of FAS whom you have seen in the last month in the UK or the Republic of Ireland.

8. Congenital ichthyosis

Case definition: Any suspected cases of severe congenital ichthyosis in live newborn or still-born babies. This includes babies with collodion membrane (a shiny film covering the skin) or harlequin ichthyosis (thick scales encasing the babies' body).

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

9. Sydenham's chorea

Case definition: According to the Jones criteria for Acute Rheumatic Fever, Sydenham's chorea is defined as "purposeless, involuntary, non-stereotypical movements of the trunk or extremities, often associated with muscle weakness and emotional lability". Sydenham's chorea is typically of acute or subacute onset, meaning that chorea reaches a peak within days or weeks rather than months. The Jones criteria include the differential diagnoses which must be excluded in order to confirm a diagnosis of Sydenham's chorea – these are listed on the notification form. Chorea is frequently a clinical diagnosis. It is important to note that laboratory confirmation of streptococcal infection provides supportive evidence of SC, but absence of such evidence does not preclude clinical confirmation. Cases may be either:

- Suspected: cases presenting with chorea with acute or subacute onset, but where no diagnosis of SC has yet been made
- Confirmed clinically: cases where a new diagnosis of SC has been made, with chorea presenting with acute or subacute onset, and lack of clinical or laboratory evidence of an alternative cause as defined by the Jones criteria.

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Reporting instructions: Please report children and young people aged 0-16 presenting for the first time to you during the reporting period with a first episode of suspected or confirmed Sydenham's chorea (i.e. with no prior diagnosis of Sydenham's chorea) whom you have seen in the last month in the UK or the Republic of Ireland.

10. Food protein induced enterocolitis syndrome

Case definition: Any infant <24 months at time of initial FPIES reaction where there was a history of :

- Repeated episodes of vomiting presenting within 4 hours after eating, where
- Removal of this food resulted in resolution of symptoms.

Excluding:

- Fever >38°C
- Any cutaneous symptoms (urticaria, angioedema)
- Respiratory features (difficulty in breathing/talking, swelling of tongue, tight throat/hoarse voice, wheeze and/or persistent cough)
- Other causes such as confirmed sepsis, an acute abdomen, gastroenteritis or cyclical vomiting syndrome.

Reporting instructions: Please report any cases seen within the last month that meet the case definition (including cases seen in clinic) in the UK and Republic of Ireland.

11. Severe complications of enterovirus or human parechovirus infection

Case definition: Any child aged <16 years with laboratory-confirmed enterovirus or human parechovirus infection (from any site) who develops any severe complication, including (but not restricted to):

- **Cardiovascular collapse** requiring inotropes (sepsis-like syndrome), or leading to myopericarditis, arrhythmias or cardiomyopathy; **OR**
- **Neurological complications lasting >48 hours:** including cranial/peripheral nerve palsy/paralysis (including acute flaccid paralysis) +/- seizure +/- coma +/- intracranial damage on imaging; **OR**
- **Fulminant or acute liver failure** requiring specialist hepatology advice/referral: including deranged liver function tests, coagulopathy and encephalopathy
- **Intensive Care admission** for management of enterovirus/parechovirus infection.

Reporting instructions: Please report any cases seen within the last month that meet the case definition in the UK and ROI.

12. Severe chronic fatigue syndrome / myalgic encephalitis

Case definition: Children aged 5 to 16 years who has been given a clinical diagnosis of CFS/ME with fatigue that is so severe that they are unable to attend school for more than one hour a week during the last 6 weeks of the school term.

Notes:

1. If a child has had CFS/ME for a long period of time, they should be reported when the paediatrician becomes aware that they are not attending school.
2. School includes hospital school but not home tuition.
3. If a paediatrician is providing assessment during the school holidays or shortly after the school holidays, they should consider whether the child is able to attend school for more than one hour (or do a similar activity) during the last 6 weeks.

Reporting instructions: Please report any cases seen within the last month that meet the case definition in the UK and ROI.