

Autoimmune Addison's Disease in Children

Surveillance to commence July 2011

OUTLINE OF THE STUDY:

Autoimmune Addison's disease is the most common cause of adrenal insufficiency in children in developed countries. Children suffering from Addison's disease are also at increased risk of other organ-specific autoimmune diseases, e.g. of the thyroid gland. If untreated the condition is life threatening and unfortunately it is not always spotted early enough.

The signs and symptoms of adrenal deficiency are steadily worsening fatigue, a loss of appetite, weight loss, low blood pressure, salt craving, emotional changes, dark pigmentation of the skin, sudden ill health and even death with a minor illness if the condition is undetected.

We intend to undertake a 13 month study to evaluate a rare condition with important clinical relevance. The current incidence of autoimmune Addison's disease in UK (under 16 years) will be identified. Clinical presentation and diagnostic strategies will be analysed and reported in the scientific literature. Variations in emergency management will be highlighted. In addition to the initial case notification questionnaire, reporting clinicians will be asked to complete a 12-month follow-up questionnaire, which will be used to collate information on the management of incident cases. Parallel reporting from the Supra-Regional Assay Service laboratories will be used to identify cases that may not be referred to a reporting clinician.

BPSU surveillance will be undertaken for 13 months, commencing in July 2011.

CASE DEFINITION:

A child will be considered to have a diagnosis of autoimmune Addison's disease if the following criteria are met:

Presence of adrenal cortical antibodies at diagnosis or confirmed subsequently

AND

One or more of the following signs and symptoms

Hyperpigmentation

Poor growth in weight and height

Electrolyte abnormalities (Hyperkalaemia, hyponaetremia, hypoglycaemia)

Addisonian crisis*

AND

Low cortisol levels with high ACTH levels

REPORTING INSTRUCTIONS:

Please report any child from birth up to but not including 16 years of age with newly presenting suspected or proven autoimmune Addison's disease meeting the case definition. If the diagnosis is awaiting confirmation, (adrenal cortical antibodies not done or awaited), the child should still be reported.

FUNDING: Sir Peter Tizard bursary

ETHICAL APPROVAL: This study has been approved by West London REC (Ref: 11/LO/0581) and has been granted Section 251 NIGB permission under reference: ECC 6-02 (FT4/BPSU)/2011.

FURTHER INFORMATION:

If you would like any advice regarding the eligibility of a particular case for inclusion in the study please contact:

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