New Zealand Paediatric Surveillance Unit Fetal Alcohol Syndrome (FAS)

Background

FAS is one of the most common causes of mental retardation. Studies from North America and Europe suggest a prevalence of 0.3-1.9 per 1000 births. Based on these overseas statistics one would predict between 20 and 112 children with FAS are born each year in New Zealand.

However, little information exists about the prevalence in NZ. A previous study estimated there were 63 children with FAS in paediatric care under 10 years of age in 1993. This figure is considerably less than the expected rate from overseas figures. It is unclear whether New Zealand truly has a lower prevalence than overseas, or whether the estimate is spuriously low due to reporting or diagnostic uncertainties, and thus falsely reassuring.

Objectives

- To estimate the incidence of diagnosed FAS among children in paediatric care in NZ
- 2. To examine the diagnostic criteria used by Paediatricians regarding reported cases
- 3. To provide data for targeting specific groups for further public health education
- 4. To provide data to inform health policy

Case definition and reporting instructions

Any child less than 15 years of age who in the opinion of the notifying Paediatrician has a new diagnosis of Fetal Alcohol Syndrome (definite or suspected)

Follow up of positive returns

A questionnaire requesting further details re the diagnostic criteria will be forwarded to practitioners who report a case.

If you have any questions please contact:

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Investigators

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Fetal Alcohol Syndrome

Diagnosis

The diagnosis of **FAS** rests with the findings of a typical set of abnormalities in 3 areas: growth, the central nervous system, and facial features in association with inutero exposure to alcohol. In the definite absence of a history of alcohol exposure, the diagnosis of FAS should not be made.

- 1. **Growth:** Growth may be deficient pre <u>or</u> post-natally. Weight is typically more affected than height.
- 2. **The central nervous system:** Evidence may be structural, neurological and/or behavioural.

Structural brain damage may be identified by microcephaly, and occasionally hydrocephalus. Structural anomalies of the corpus callosum, grey matter, white matter, or cerebellum may be found on CT or MRI scan in some patients.

Neurological: seizures or abnormal findings on EEG, abnormalities of muscle tone (hypertonia, or hypotonia), tremors or marked incoordination, sensorineural hearing loss, visual problems (myopia or hyperopia).

<u>Behaviour</u>: FAS is characterised by complex behavioural and/or learning problems that are not fully explained by genetic background or environmental influences and are resistant to improvement with the usual types of interventions. Specific problems include attention deficit disorder (with or without hyperactivity), impulsivity, problems with reasoning and judgement, learning disabilities, speech and language delays, dyslexia, mild mental retardation, or an IQ below familial expectation.

3. Facial features: The FAS facial phenotype is typically characterised by short palpebral fissures, a flat midface, a thin upper lip, and a smooth philtrum. Less common features include epicanthal folds, ptosis, high arched eyebrows, and a short upturned nose. Palpebral fissure lengths are adjusted for age, measured in standard deviations from the norm, and are best obtained from upward-looking eyes (see enclosed chart). Lips should be gently closed with no smile. The FAS phenotype often diminishes with age, and tends to be most clearly expressed between the ages of 2 and 10 years.

A relationship to prenatal alcohol exposure should be sought. Exposure can be classified as high risk, some risk, unknown risk or no risk.

High risk: there is a report by the birth mother or directly from another individual who saw the mother drink during pregnancy \underline{and} exposure likely to produce blood alcohol concentrations >100mg% weekly (\geq 4 standard drinks in one sitting), in the first trimester of pregnancy.

Some risk: there is a report by the birth mother, other direct observer, or reliable source <u>and</u> drinking occurred in gestation in frequencies and volumes less than the amount in the high risk category.

Unknown risk: gestational exposure is simply not known or information is of uncertain reliability.

No risk: the mother reliably acknowledges no exposure to alcohol in pregnancy, or minimal exposure (i.e. 1 drink less than once per month).