

## A B S T R A C T

The incidence of fetal alcohol syndrome (FAS) in northeastern Manitoba was investigated by examining all 745 live births occurring in Thompson General Hospital in 1994. Birth records were screened with criteria designed to capture all potential FAS cases. Cases were then eliminated if follow-up records indicated the child was not developmentally delayed or no longer had the small head or body size identified at birth. Cases still meeting criteria were personally examined. Five cases of FAS were identified among the 46% of eligible children screened at age 2, roughly an incidence of 7.2/1,000. However, because only 46% of the high risk cases were personally examined, incidence could be as high as 14.8/1,000. Only 1/5 FAS cases had been identified prior to our investigation. The results indicate the incidence of FAS in northeastern Manitoba is very high and that much greater effort needs to be made in its prevention and early detection.

## A B R É G É

L'incidence du syndrome d'alcoolisme foetal (SAF) dans le nord-est du Manitoba a été étudiée en examinant les 745 naissances vivantes de l'hôpital général de Thompson en 1994. Les naissances enregistrées ont été examinées avec des critères conçus pour détecter les cas potentiels de SAF. Ensuite, on a éliminé les cas enregistrés où l'enfant n'avait pas de retard dans son développement et ceux dont la taille du corps ou de la tête était anormalement petite à la naissance mais dont le problème s'est résorbé par la suite. Ensuite, les cas répondant encore à nos critères ont été examinés. Cinq cas de SAF ont été identifiés parmi les 46 % des enfants éligibles examinés à l'âge de 2 ans, représentant une incidence de 7,2/1 000. Cependant, parce que seulement 46 % ont été examinés, l'incidence réelle pourrait être de 14,8/1 000. Avant notre recherche, seulement 1/5 des cas de SAF avait été identifié. Donc, les résultats indiquent que l'incidence du SAF dans le nord-est du Manitoba est élevée et un effort important doit être fait pour le prévenir et le détecter rapidement.

# Incidence of Fetal Alcohol Syndrome in Northeastern Manitoba

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Drinking alcohol during pregnancy can result in a variety of birth defects known as fetal alcohol syndrome (FAS). This syndrome is defined by growth deficiencies (height and/or weight < 10th percentile), central nervous system impairment (developmental/intellectual delay, small head for body size, behavioural disorders), and characteristic facial features (e.g., short eye openings, thin upper lip, flattened philtrum).<sup>1</sup> The occurrence of FAS depends on several factors, including amount of alcohol consumed, nutrition and health of the mother, genetic susceptibility, use of other drugs, and possibly race.<sup>2,3</sup>

The incidence of FAS has been investigated in Sweden,<sup>4</sup> Australia and New Zealand,<sup>5</sup> the United Kingdom,<sup>6</sup> the United States<sup>7</sup> and Canada.<sup>8</sup> FAS rates are variable between sites, but a conservative estimate is that 0.33 cases occur in every 1,000 births in western countries.<sup>9</sup>

There are five studies looking at the rates of FAS in Canada. Wong in 1983<sup>8</sup> estimated the incidence of FAS in British Columbia to be 0.25/1,000 for non-Aboriginals and 4.7/1,000 for Aboriginals. Habbick, Nanson, Snyder et al. estimated the incidence of FAS in Saskatchewan to be 0.5/1,000 in 1973-1977 and 0.6/1,000 in 1988-1992.<sup>10</sup> Robinson, Conry & Conry<sup>11</sup> in 1987 found a prevalence rate of 190/1,000 FAS on an Aboriginal reserve in British Columbia. Asante & Nelms-

Matzke<sup>12</sup> in 1985 found an FAS/FAE prevalence of 0.4/1,000 among non-Aboriginals in northwestern British Columbia and a rate of 46/1,000 among Aboriginals. A very recent study on a northern Manitoba Aboriginal reserve found a FAS/FAE prevalence rate of 95/1,000.<sup>13</sup>

Part of the variability in rates reflects different patterns of alcohol abuse in different sites. However, there are also several methodological problems affecting rates. For example, incidence studies that rely exclusively on birth records<sup>7</sup> likely underestimate rates because the facial features and central nervous system problems often are not as apparent until children are older. Studies that follow pregnant mothers<sup>14</sup> tend to underestimate rates because women who are at greatest risk for FAS babies often do not receive prenatal care. Prevalence studies that do comprehensive assessments of all children in one particular site<sup>11</sup> tend to produce higher rates because they have chosen sites where FAS is expected to occur more often. Some studies have combined the assessment of FAS with the assessment of fetal alcohol effects (FAE),<sup>12</sup> which is considerably more common and has more ambiguous diagnostic criteria. Studies which base their rates solely on children who are referred for assessment<sup>12,15</sup> may miss mildly affected children and children unknown to the referral agents.

The primary purpose of the present investigation was to use improved case-finding methodology to identify and provide services to any FAS children who were not currently receiving services. There were two secondary benefits to this clinical investigation. The first was the ability to better estimate the actual incidence of FAS

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in northern Manitoba. The second was the ability to examine the effectiveness of current systems in identifying FAS.

## METHOD

Thompson, located 750 km north of Winnipeg, is the third-largest community in Manitoba and one of Canada's largest population centres north of the 55th parallel. It is a mining town and in 1993 the population was 15,300. Thompson is the "hub of the north", and there is also a large transient population from the many surrounding reserves and towns seeking employment, services and medical care. Thompson General Hospital is the main hospital serving northeastern Manitoba, with a catchment area of roughly 50,000 people. The majority of women from northeastern Manitoba who give birth do so in this hospital.<sup>16</sup> Most of the babies are of Aboriginal descent, which reflects the general demographic nature of northern Manitoba.

The present investigation examined hospital records for all live births occurring in Thompson General Hospital in 1994. The year 1994 was chosen as the children would be approximately 2 years old by the time they were examined in 1996 so that any FAS facial features, growth retardation or developmental delay would be more readily apparent. All records for 1994 were available and well documented. Cases were screened with broad criteria designed to capture all potential FAS cases. Specifically, children were eliminated from further analysis if their birth records did not indicate one or more of the following features:

- Birthweight less than 3000 gm (25th percentile).
- Head circumference equal to or less than 33 cm (10th percentile).
- Maternal alcohol abuse during pregnancy (as noted by the clinician or reported by the mother).
- The mother reported any alcohol use during pregnancy, and there was a birth or pregnancy complication commonly associated with FAS (i.e., breech presentation, cesarean section, gestation  $\leq$  37 weeks, or 5 minute Apgar score  $\leq$  7).

**TABLE I**  
Frequency of Various Features in the Birth Records (N=745)

	n	(%)
Birthweight < 3000 gm	122	(16)
Head circumference at birth $\leq$ 33 cm	113	(15)
Mother reported consuming alcohol during pregnancy	196	(26)
Mother reported smoking tobacco during pregnancy	440	(59)
Gestation $\leq$ 37 weeks	85	(11)
Breech presentation or cesarean section	53	(7)
5 minute Apgar score $\leq$ 7	20	(3)

Cases having one or more of these characteristics were further scrutinized by examining available follow-up hospital or public health records from either Thompson or the child's home community. Most children had 3 to 5 post-natal visits in their charts (all had at least one) that provided information on physical measurements at these times, and usually also developmental status on the Denver Developmental Screening Test at some point. Cases were eliminated from further analysis if follow-up records indicated any of the following:

- The child was no longer below the 25th percentile for weight (if low birthweight was the basis for their initial inclusion).
- The child was no longer below the 10th percentile for head circumference (if small head circumference was the basis for their initial inclusion).
- Developmental screening showed no evidence of developmental delay.

All cases still meeting these secondary screening criteria were slated for individual examination by one of the two local Thompson pediatricians. Fetal alcohol syndrome was diagnosed if height and/or weight was less than the 10th percentile (when corrected for gestational age), there was evidence of central nervous system impairment (developmental delay or small head for body size), and if at least two characteristic facial features of FAS were present.

It should be noted that the above methodology meets all the criteria recently recommended by Sampson, Streissguth, Bookstein, et al.<sup>17</sup> to more accurately determine incidence (i.e., using all liveborns as the denominator for incidence; using the 1996 Institute of Medicine's diagnostic criteria for FAS; retaining cases with no report of alcohol exposure; and establishing the FAS diagnosis between 8 months and 8 years).

## RESULTS

In 1994 there were 745 live births in Thompson General Hospital from 22 different cities, towns and reserves from the 54th to 60th parallel in northern Manitoba. Of these births, 192/745 cases met the initial screening criteria of either having low birthweight, small head circumference, alcohol abuse, or alcohol use plus an associated complication. Table I details the frequency of each of these features.

Of the 192 cases meeting the initial screening criteria, 102 were excluded from further analysis because follow-up hospital or public health records showed their weight was no longer below the 25th percentile, or their head circumference was no longer below the 10th percentile, or because developmental testing found no evidence of developmental delay.

Of the remaining 90 cases, 41 children were examined in person. Forty-nine children were not examined either because the remoteness of the home community made examination too difficult (n=16), the child could not be located (n=8), or, in one case, because the community did not grant permission for the pediatricians to visit (n=25). (Although community consent was not sought, there was one community that became aware of our work and expressly asked the pediatricians not to conduct FAS assessments on the reserve, despite reassurances that the community of origin for FAS cases would not be identified).

Of the 41 children who were examined, 5 were diagnosed as having fetal alcohol syndrome. The details of these 5 cases are presented in Table II. All cases were either Aboriginal or Metis. Birthweight averaged 2398 gm. Birth head circumference averaged 32.1 cm. Gestation averaged 38.4 weeks. Only one case had been previously diagnosed. Two of the children had been

TABLE II  
Characteristics of Identified FAS Cases

Case	1	2	3	4	5
Race	Native	Metis	Native	Native	Native
Birthweight (gm)	1760	2382	2698	2841	2307
Birth head circumference (cm)	31	31.5	33	33	32
Gestation (weeks)	36	40	39	39	38
Breech or c-section	no	no	no	C/S	no
5 minute Apgar $\leq$ 7	no	no	no	no	no
Alcohol in pregnancy	heavy	abuse	yes	yes	yes
Smoking in pregnancy	yes	yes	yes	yes	yes
Dx prior to our involvement	yes	no	no	no	no
Guardianship at ascertainment	parents	FamSer	parents	parents	FamSer
Services at ascertainment	yes	no	yes	no	yes

apprehended by Manitoba Family Services and one other was apprehended soon after. Three of the children were receiving services at the time of ascertainment (2 receiving medical care and 1 receiving infant stimulation).

## DISCUSSION

The present study found 5 cases of FAS out of a population of 696. This roughly translates into an incidence of 7.2 per 1,000, although the raw numbers are too small to be certain about actual incidence. Nevertheless, it is instructive to compare this figure to rates elsewhere. It is considerably higher than estimated international rates (0.33/1,000),<sup>9</sup> and is also somewhat higher than what has been found in the North American Aboriginal population before (2.8-6.6/1,000).<sup>18</sup>

It should also be noted that the incidence of FAS found in the present study is almost certainly an underestimate of the actual rate in northern Manitoba. Although 93.4% of all eligible children were screened, only 45.6% of the high risk cases were examined (41/90). If the rate is the same in the unexamined group as it was in the examined group, then the actual incidence would be 14.8 cases per 1,000 (or likely higher as difficult-to-locate individuals often have higher rates of the condition being investi-

gated). A second consideration is that only 57% of babies born to northern Manitobans occur in Thompson. There are several reasons for this, but one of the more important ones is that most high risk pregnancies (presumably including some FAS cases) are transferred to Winnipeg.

It seems clear that the incidence of FAS and FAE in northern Manitoba is quite high and of concern. If nothing else, the frequency of new mothers reporting consumption of alcohol during pregnancy (26%) is disturbing. This, too, is likely an underestimate, as a recent study found that 51% of Aboriginal women in northern Manitoba retrospectively reported consuming alcohol during one or more of their pregnancies.<sup>19</sup> Of equal concern is the fact that 4/5 of the FAS children had not been previously diagnosed and 2/5 were not receiving any services prior to their detection. It would appear that greater efforts need to be made both in the prevention of FAS and in its early detection.

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