Appendices

Original questionnaire distributed to parents/caregivers of children with FACS in Aotearoa New Zealand.

Dear Parent/Caregiver

As you may be aware, there are many known features associated with the Foetal Anticonvulsant Syndrome (FACS). Although limited, there is current evidence in literature that suggests that abnormalities related to the face, mouth and teeth may also be associated with FACS. At the University of Otago, we are conducting research of these associations and would like to know about your observations and first-hand experience. Please fill in the questionnaire below relating to any features of the face, mouth and teeth that you have observed in your child. If you have more than one child with FACS, please complete a separate questionnaire for each child. Your answers are valuable to our research and will be used solely for the purpose of directing further research.

1) Personal information (child):

Date of birth:.....

Gender:.....

Ethnicity:.....

2) When was your child diagnosed with Foetal Anticonvulsant Syndrome?

Child's age: .....

3) Please state the name(s) of the anticonvulsant medications that you were taking during the pregnancy:

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4) Please tick the relevant features of FACS currently seen in your child:

Irregularities of the eyes, ears, lips and nose

Irregularities of organs or limbs

Cognitive disabilities/Autism spectrum disorder

Other

Please explain if you have ticked Other:

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5) Have you noticed any problems with the way your child eats, speaks or swallows?
Please explain what you have noticed:

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6) Have you noticed any problems with your child's teeth?
Please explain what you have noticed:

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7) Have you noticed any differences in the appearance of your child's face and/or teeth compared with other children of his/her age?

Please explain what you have noticed:

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8) Does your child attend routine dental care?

Yes

No

9) Does your child cope well in the dental setting?

Yes

No

If you have answered no, please briefly explain the problems encountered during your child's dental visit:

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10) Does your child have a history of a cleft lip and/or palate?

Yes

Please explain:

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No

11) Additional comments or concerns relating to your child's dental and facial features:

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Thank you for participating in this questionnaire.
We appreciate your time and your responses are very valuable to our research.