



THE PAEDIATRIC SOCIETY OF NEW ZEALAND

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For the attention of The National Screening Unit of the Ministry of Health:
Wendy Reid (Wendy_reid@moh.govt.nz)
and Sian Burgess (Sian_burgess@moh.govt.nz)

Regarding the

- Updated guidelines for health practitioners for antenatal screening for Down Syndrome and other conditions
- Revised consumer pamphlet for pregnant women.

Dear Wendy and Sian

Thank you for giving us the opportunity to feed back on the proposed updated guidelines and consumer pamphlet regarding antenatal screening for Down Syndrome and other conditions. It is obvious that a lot of work has gone into preparing these documents including consultation with relevant stakeholders. This submission has been prepared by participants in the Community Paediatrics Programme of Excellence and is endorsed by the Paediatric Society of New Zealand. We have reviewed these documents and would like to share some of our thoughts.

Guidelines

- Measurement of the nuchal thickness at 12 weeks gestation is not reliable enough a screening test without the blood test due to high false positive results. This is not stated clearly in the guideline and perhaps should be brought to the attention of healthcare providers more strongly so that false assurance is not given on that basis regarding risk stratification.
- We have identified the potential for significant barriers to equity of access to screening:
 - The first trimester test is already biased in favour of those women who are able to access early maternity services. Although this is an inherent bias, the part-charge (of approximately \$30) on the ultrasound would further disadvantage women from lower socio-economic backgrounds, especially including some Maori and Pacific Island families. This needs to be taken into account and perhaps the ultrasound scan subsidized further, even if not for all women.
 - Much of the information that needs to be relayed by the health care provider is complex, and cultural and linguistic barriers may further impede true informed consent. We suggest that the parent information pamphlet be made available in a number of languages. Health care workers will need to be aware that cultural supports may be necessary in some cases during the screening process.

- The flow chart on page 11 reads 'continue management of pregnancy' if the woman declines screening but perhaps this would better read as 'continue with the usual management of pregnancy.'
- We are concerned that women with increased risk, being referred to a specialist service, should explicitly state if they do not wish to have an amniocentesis. They may be triaged to a lower priority as there is no urgency for termination. We recommend having a written guideline suggesting how long it would be reasonable to wait for the specialist appointment given that this is likely to be a frightening and stressful time for most. It is also important to note that a woman may change her mind about amniocentesis in the meantime but have her choices reduced by having been triaged differently.

Consumer pamphlet

Overall we felt that the pamphlet was very good. However, it has the difficult task of presenting a very complex topic in a concise yet easy-to-read-and-understand format. We felt that by endeavouring to approach this topic sensitively the pamphlet has turned out to be wordy, yet vague, in its messages. The potential difficulties children with Down syndrome may experience appear to have been played down. We do recognize the difficulty in striking a balance of what the appropriate amount of information is but true informed consent requires us to be as factual as possible.

- The pamphlet suggests that Down syndrome 'may cause' health problems whereas it would be more accurate to state that it is 'likely to cause health problems, which may range from minor to more serious.'
- There is a real risk of congenital life-threatening cardiac lesions and the general public is likely to be unaware of this. Providing some risk estimates of cardiac abnormalities (mild and severe) would be meaningful to parents.
- The term 'developmental delay' is poorly understood by many readers and so we suggest using the phrase 'intellectual disability.'
- Although it is accurate to state that 'many of these problems can be treated,' this may be misleading. Treatment is not necessarily curative but it could be interpreted as such by many.
- It is important to emphasize that there is support available for families with a child with Down syndrome and also that most people with Down syndrome attend school and join in family / whānau and community life.
- It should be explicitly noted that a woman choosing not to undergo screening will not have her maternity care affected in any detrimental way.

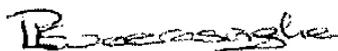
General considerations

- The online learning modules were very good but many links were not working. One area that was not covered well was that of communicating risk. More resources could be added to address this.
- We recommend that it be compulsory for LMCs to participate in the online learning modules as they are at the forefront of communicating the complexity of this topic. The implications of poor communication could truly be life-changing, regardless of the decision a woman came to regarding screening and the implications thereof.

- The concept of risk has an individual and subjective interpretation. We would like to see screening results reported with a description of the test's overall sensitivity and specificity e.g. 'X% of Down Syndrome is detected on this screening, but X% of affected pregnancies will return a low risk result.' This may give additional understanding to parents and professionals and also reinforce the idea that 'low risk' is not 'no risk.' However, given that the pre-test probability varies between women, the screening test result would also vary. This may not be something well-understood by the health professional and a risk assessment tool in the guideline would aid in the decision process.
- Also with regard to risk, the divide between low and high risk seems arbitrary e.g. low risk if 1:299 but high risk if 1:301. Would it be more useful to categorize into three groups of low, intermediate and high?
- Research suggests that first trimester screening is better than second trimester quadruple screening if done at 11 weeks gestation, but similar if done at 13 weeks¹. We therefore suggest explicitly stating that the first trimester screening is the preferred option. Women also need to be made aware of both the medical and legal implications of early termination compared to late, if they chose to follow that decision. There does not seem to be any information around this.
- There is also evidence to suggest that combining first and second trimester results increases the sensitivity and specificity of screening and reduces the number of women requiring invasive testing².

So in conclusion, the cost-effectiveness of a combined screening programme merits exploration so that unnecessary amniocenteses can be avoided.

Yours sincerely



Dr Kalhari Weerasinghe
On behalf of Community Child Health
New Zealand Programme



Dr Rosemary Marks
President
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¹ N Engl J Med. 2005 Nov 10;353(19):2001-11.

² Semin Perinatol. 2005 Dec 29(6):367-75