

## Researchers now accessing Guthrie cards

Since June 2011 researchers have been able to obtain approval from ethics committees for research that involves accessing residual blood spots on Guthrie cards without having to obtain consent from parents or the adult individual whose card it is. Prior to this, researchers had to get written consent from the individual as well as Ethics Committee approval, review by the Newborn Metabolic Screening Programme Governance Team and Ministry of Health permission before the cards could be released for population research.

It is difficult to know how many parents are aware that the protocols around accessing Guthrie cards have changed, as there is no monitoring of how many new parents are given the National Screening Unit's (NSU) booklet and have read and understood that their baby's Guthrie card will be permanently stored in what is essentially a biobank, and can be used by researchers without their knowledge or consent.

The NSU's 8-page booklet contains one brief mention of the fact that the stored blood spots can be used "for research approved by an ethics committee." (1) There is a little more information on the NSU website: "For blood spot samples collected after June 2011, any applications for population research must first be approved by an ethics committee and then is reviewed by the Newborn Metabolic Screening Programme Governance Team." (2) However, given the vested interests involved there needs to be a completely independent review.

One such research proposal was recently approved by the Northern A ethics committee during its August meeting. Given the type of research involved – a study of the natural history of around 120 children born between 2006-2012 who had elevation of a chemical suggestive of a condition known as VLCAD deficiency on the initial newborn screening test – the ethical thing to do would have been to have sought consent from the parents of these children. Unfortunately, the parents will never know their child's card was accessed and used, or what the study revealed.

### References

1. [http://www.nsu.govt.nz/files/ANNB/Your\\_newborn\\_babys\\_blood\\_test.pdf](http://www.nsu.govt.nz/files/ANNB/Your_newborn_babys_blood_test.pdf)
2. <http://www.nsu.govt.nz/current-nstu-programmes/2917.aspx>

