Your Newborn Baby’s Blood Test

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Outline

• Background – newborn screening in New Zealand – why develop a new information sheet?
• Development process
• The new brochure
• 4.4 M population
• 65000 births per year
  – European 54%
  – Maori 22%
  – Pacific peoples 11%
  – Asian 10%
  – Other 3%
• All screening, diagnosis and treatment government funded
• National Screening Unit
• Specialist unit within Ministry of Health
• Funds screening through contract with local hospital laboratory
Parent information

- Available since 1980
- Revised at 5-7 year intervals

- Most recent revision November 2010 coordinated with development of policy framework and practitioner and parent DVDs
2005

• Public consultation on storage and use of residual dried blood spots
  – Focus groups
  – On-line surveys
  – Stakeholder workshops
• Expert advice
• Outcome
  – Destroy all immediately
  – Save all for every possible research
  – And everything in between
2006 -> 2011

- Ministry of Health Options paper
- Sent to Cabinet Social Policy Committee
- Decided on permanent retention but
  - New Governance team for programme
  - New process for requesting access for research (approval of Governance team as well as Ethics Committee)
  - Research use of samples collected before June 2011 must have consent. After that time consent implied as to be more thoroughly covered in information sheet
Policy Framework
June 2011

• Return of residual spots to family
• Storage and use
  – Separate consents
  – Primary uses
  – Secondary uses
  – Family health uses
  – Police use – separate MOU
  – Coroner
  – Mortality review
  – Research uses
• Research application form
• Process flowchart
Informed consent

- Consent must be obtained
- Separate consent for collection and storage of samples
- Verbal consent sufficient if documented ideally in baby’s notes, otherwise mother’s
Primary uses

• Screening newborns
  – First test
  – Repeat confirmatory testing
  – Investigation of false +ve and –ve
  – Programme QA and audit
  – Assay improvement and test validation for current disorders
  – Test validation for potential new disorders
Secondary uses

• For the benefit of the baby and family eg congenital cmv
• Forensic / police investigations
• Coroner investigations
• Mortality review
• Research
• Other
Rauemi Atawhai

- MOH guide to developing health education resources in New Zealand
  - Be prepared
  - Be clear on your audience and your key messages. Language level
  - Be relationship focused
  - Test, test and test again with your audience and stakeholders.
  - Pictures not cartoons
Process

- Contract let to commercial company
- Text review, design development
- Pretesting – 40 people NZ European, Maori, Pacific, Asian – range of locations
  - Clarity
  - Understanding of messages
  - Usefulness
  - Cultural appropriateness
  - Relevance
  - Appeal
  - Design
• NSU consultation with key stakeholders including consumers, members of the NMSP Advisory Group, professional bodies
• Completion of photo shoot for new photos for the pamphlet - required signed consent for use.
• Final review and editing
• Printed November 2010
Your newborn baby's blood test

The Newborn Metabolic Screening Programme
• About the programme

• Why screen?

• Who should be screened (not compulsory but strongly recommended by the Ministry of Health

All babies are checked at birth to see that all is well. Some of your baby’s health checks are called ‘screening’.

The Newborn Metabolic Screening Programme

The Newborn Metabolic Screening Programme detects rare but life-threatening metabolic disorders with a blood test done at 48 hours old or as soon as possible after this. Since 1969, almost all babies in New Zealand have had this screening. Early diagnosis means that treatment can start quickly, before the baby becomes sick. Metabolic disorders are hard to find without screening.

Why screen for metabolic disorders?

Screening saves lives. Each year, about 45 New Zealand babies are found to have a metabolic disorder. Although these disorders cannot be cured, early treatment with medication or a special diet can help your baby stay well and prevent severe disability or even death.

Metabolic disorders can occur in any family, even when there is no family history of disorders. Screening is an important way of identifying babies who are more likely than other babies to have a disorder.

Who is newborn metabolic screening for?

Newborn metabolic screening is offered free for babies born in New Zealand. Your midwife or doctor will talk with you during pregnancy about screening for your baby.

The Ministry of Health strongly recommends screening for your baby.
• How is the sample collected?

• Can choose return of residual sample

• How results will be given

• Why are repeats needed?

• About positive results
• Screening process
What are stored spots used for?
- Repeat testing
- Screening lab uses
- Research approved by an ethics committee
- Family health reasons

How do I get spots returned to me?

Storage and use of leftover blood spots

Any blood left over after screening is either securely stored or returned to you. Blood is stored to assist with maintaining a high-quality screening programme and for other uses.

What can the stored blood spots be used for?
The stored blood spots may be used:
- for repeat testing. If your baby has a disorder but did not have a positive test result, the blood sample can be tested again to see why this happened.
- to improve the screening programme, such as by making sure that testing equipment produces accurate results
- for research approved by an ethics committee
- to investigate a death or illness in your family.

The stored blood spots will not be used for anything else without written consent from the parents or guardians or from another lawful authority such as if ordered by a court. More information is available at www.ns.govt.nz

How do I get leftover blood spots returned to me?
You can ask your midwife or doctor to arrange for the leftover blood spots to be returned to you by sending a signed request with the blood spot card. Alternatively, leftover blood spots can be requested at any time using the form 'Return of Newborn Metabolic Screening Samples' available at www.ns.govt.nz
What information is collected and how is it used?
As part of newborn metabolic screening, basic information about your baby is collected and stored. This includes your baby’s name and address, sex, ethnicity and weight, and where and when your baby was born. Your name is also recorded. The programme holds this information securely and confidentially.
The information is used to:
- interpret screening results
- make sure that results can be given to your midwife or doctor
- check that babies have been screened
- monitor the screening programme.

The Ministry of Health collects information for monitoring and evaluation of the screening programme. Your decisions about screening will be recorded in your maternity and Well Child Tamaki Ora notes. If you choose not to have your baby screened, you will also be asked if this information can be sent to the screening programme.

What are my rights?
The Code of Health and Disability Services Consumers’ Rights protects your rights. You can read more about these rights at www.hdc.org.nz

The Health Information Privacy Code protects your privacy. You can read about the code at www.privacy.org.nz

What metabolic disorders are babies screened for?
Babies are screened for over 20 treatable disorders. A full list of the disorders is available at www.ns.govt.nz

Aminoacid disorders, eg, phenylketonuria (PKU)
Caused by: a missing enzyme. Without these enzymes, amino acids (such as phenylalanine) rise to harmful levels
Can lead to: brain damage and life-threatening complications
Treated by: special diet
Occurs in: about 5 babies every year

Fatty acid oxidation disorders, eg, medium chain acyl-Co A dehydrogenase (MCAD) deficiency
Caused by: a missing enzyme. Without these enzymes, the body cannot break down fats to make energy
Can lead to: life-threatening complications
Treated by: ensuring regular feeding [a special diet is needed in some disorders]
Occurs in: about 5 babies every year

• What information is collected?
• How is it stored and used?
• What are my rights?
• What conditions are screened for?
  – Aminoacid disorders
  – Fatty acid oxidation disorders
• What conditions are screened for
  – Congenital hypothyroidism
  – Biotinidase deficiency
  – Cystic Fibrosis
  – Galactosemia
  – Congenital adrenal hyperplasia

• Headings
  – Caused by
  – Can lead to
  – Treated by
  – Occurs in

The Newborn Metabolic Screening Programme is committed to the highest possible standards. To maintain the quality of the programme, disorders screened for are reviewed and the programme is closely monitored. Further details are available at www.esu.govt.nz
More information

It is important that you have enough information to help you decide about newborn metabolic screening. If you would like more information:
- ask your midwife or doctor
- check online at www.nsu.govt.nz

Your midwife or doctor can provide you with a DVD about newborn metabolic screening, or you can view this at www.nsu.govt.nz

The Newborn Metabolic Screening Programme is overseen by the National Screening Unit of the Ministry of Health.

• How to get more information
Information sheet complemented by

- Best practice DVD for families
- Disorder positive information sheets
- For healthcare practitioners
  - Guidelines
  - On-line learning
Resource availability

- Your Newborn Baby’s Blood Test
- On-line learning
- DVDs
- Guidelines
- Policy Framework
- Monitoring Framework

Thank-you