



# ON TRACK Network Forum for Women & Whānau



ON TRACK NETWORK  
BETTER HEALTH FOR MOTHERS AND BABIES  
Te Awhi Rito

## Te Awhi Rito

Better Health for Mothers and Babies

**Kia ora**, welcome to the ON TRACK Network Forum for Women & Whānau newsletter. The ON TRACK Network is a New Zealand-wide clinical trials network. We connect with people from across the whole country who are interested in clinical trials research that aims to improve the health and wellbeing of mums and babies. This includes midwives, obstetricians, neonatologists, nurses, researchers, hospital managers, funding agencies, policy-makers, **and most importantly, consumers – the mums and babies we do the research for.** We produce this quarterly newsletter for you, but to make our Forum easily accessible to everyone, most of our activity runs through our Facebook page. Please take a look and join in: [www.facebook.com/ontracknetwork](http://www.facebook.com/ontracknetwork)

### Ways to be involved

Like our **Forum's Facebook page** and become part of the conversation.

Join our Forum's **contact list**

Attend our annual **Trial Development Workshops**.

Contribute to our **newsletter** by emailing us.

Follow us on **Twitter @ONTRACKNetwork1**.

Join our **Research Prioritisation Project** and tell us what is important to you.

Watch out on our Facebook page for invites to join specific projects.

**Contact us at any time:**  
[ontracknetwork@auckland.ac.nz](mailto:ontracknetwork@auckland.ac.nz)



**Would you be happy for your healthy baby to have regular heel prick blood samples as part of a research study? Seventy families in the GLOW Babies Study were. As part of the research parents were asked about their experience.**

Measuring a newborn baby's blood sugar (known as glucose) level is routinely done for babies that are born prematurely, are particularly big or small, or, if their mums have diabetes. But, believe it or not, until very recently doctors and nurses didn't know what the normal blood glucose level was for *healthy* newborn babies. The **Glucose in Well Babies (GLOW) Study** set out to answer this question by working with families in the Waikato region to measure regular blood glucose levels in their healthy newborn babies. At the end of the study, mums and dads were asked to complete a questionnaire about the experience. Doing extra tests on babies for research purposes can be difficult because new parents may feel reluctant to get involved. Learning what works for parents helps us to plan future research.

**What did the research involve?** In the first 5 days of life, GLOW babies had regular heel-prick blood samples taken (up to a maximum of 16) and continuous glucose monitoring, which required a special monitor to be inserted under the skin of baby's thigh. All families completed the study in their own home and so many of the blood tests were performed by the research team making regular home visits. Parents were asked to record all of baby's feeds using an app on a study-provided smart phone.



#### What did we learn from 131 mums and dads of 70 GLOW babies?

- 96% reported they liked contributing to improving healthcare
- 91% liked the support from the GLOW Babies team
- 97% would participate in GLOW Babies again if they had another eligible baby
- 100% would recommend GLOW Babies to family and friends
- 66% reported that participation had made them more likely to contribute to clinical research in the future.

These positive responses from GLOW Babies parents are reflected in the fact that all babies remained in the study for the full 5 days.

What mums and dads said:

*"we felt privileged to help"*

*"the quality and support of the research team made it a rewarding experience"*

*"thank you so much, participating was just reciprocal considering all the support and care we got"*

*"it was important to do this"*

This suggests parents who understand the rationale for clinical research and feel supported to be involved, report a positive experience after participation even with such invasive research on their newborn. **This gives reassurance to parents, clinicians, researchers and ethics committees that invasive non-therapeutic clinical studies (without any possibility that the individual baby participating would benefit from the research) are feasible and can be acceptable to parents.**

The GLOW Babies Study was only possible because 70 families were prepared to involve their babies in ground-breaking non-therapeutic research. These parents recognised the value of this research and the benefit to future families. If you would like to find out more, please visit the GLOW Babies Facebook page [facebook.com/glowbabiesstudy](http://facebook.com/glowbabiesstudy) and our Facebook page [facebook.com/ontracknetwork](http://facebook.com/ontracknetwork)

Share Your Story!

Do you have a clinical trial story to share? We would love to hear from you.

You can email us: [ontracknetwork@auckland.ac.nz](mailto:ontracknetwork@auckland.ac.nz)  
Or, join us on Facebook:



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## What is Research Prioritisation?

You may have noticed that one of the ways suggested to get involved with our Forum is to take part in our [Research Prioritisation Project](#), but what exactly is this? We caught up with some of the ON TRACK Network Research Prioritisation team, Jody Lawrence and Clara Mossinger, to find out.

Research tells us how to best provide healthcare and how to deal with complications or illness. This is also true for women's and babies health during pregnancy, at birth and postnatally. Until recently researchers and funders decided what research was done but are they really the only people to decide? Newer ways have been developed to seek opinion from a much wider group, and to use tools that help to weigh different criteria depending on their importance, for example, equity and burden of disease. This prioritisation of research helps us to use our limited resources to get the best health benefits for the population, i.e. **it tells us where we should be focussing our efforts and money.**

The ON TRACK Network Research Prioritisation team have looked at the many different methods of research prioritisation and developed one specifically for New Zealand and our mothers and babies health. One of the key features is **the inclusion of women, parents, caregivers and whānau** in the process. We believe that you are in a very strong position to identify what future research questions we need to ask.

**How can you get involved?** One of the first steps in the process is to find out what we don't yet know. These are called 'knowledge gaps'. We will be using on-line questionnaires and small focus group discussions or interviews to ask midwives, doctors, nurses, researchers, funders and policy-makers to tell us what their

knowledge gaps are across preconception health, pregnancy loss, antenatal care, labour care, postnatal care and newborn health.

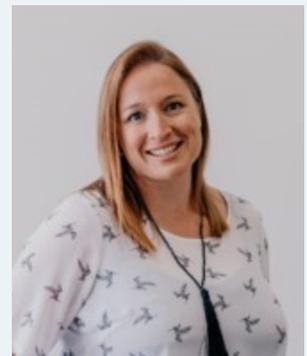
**We would love you all to join this too. Links to our questionnaire and opportunities to join focus groups and interviews will be advertised on our Facebook page and through our Forum contact list soon, please get involved and please pass on to your friends and whānau** (your contributions will be anonymised and not traceable back to you).

Once we have collected all the knowledge gaps, we will work these into research questions that will be collated and ranked using five criteria. Our Ranking Group includes consumers and Māori and Pacific health experts, as well as clinicians and researchers from all around the country.

This is a great opportunity to shape the future direction of better health for mothers and babies in New Zealand. **Please join us.**



Clara Mossinger (left) is a midwife with a master's degree in public health. She is completing her PhD in research prioritisation at the Liggins Institute, University of Auckland.



Dr Jody Lawrence (right) has a background in public health and recently joined the ON TRACK Network team as the Research Prioritisation Project Team Leader.



**C\*STEROID**  
FEASIBILITY

## New Zealand Research: The C\*STEROID Feasibility Study

Babies that are born early (preterm) have higher risks of breathing problems. Corticosteroids are routinely given to the mothers of these babies when it is suspected they will be born before 35 weeks as there is good research evidence that this improves these breathing problems. We also know that babies born by a planned caesarean section, even later in pregnancy, have a higher risk of short term breathing problems compared to babies born by vaginal birth. What we don't know is, if corticosteroids have the same effect for these babies.

We are planning a New Zealand-wide clinical trial to answer this question. The C\*STEROID Trial will invite women having a planned caesarean section from 35<sup>+0</sup> to 39<sup>+6</sup> weeks to get involved and receive two doses of corticosteroid or a placebo (dummy). By the end of the study we will be able to accurately assess the benefits and any harms of this treatment, this evidence will be enough to direct future care both in New Zealand and globally.

But this is a big job, we will need more than 2500 mums and babies to get involved. So to make sure we do this as efficiently as possible we have spent the last nine months completing the C\*STEROID Feasibility Study. We have run the trial in Waikato, Tauranga and Auckland City Hospitals. From this we are learning from the mums that say 'yes' and the mums that say 'no', as well as clinicians and researchers about what works well and what we can do better. We will use all this information to make the trial as easy as possible to join and take part in.

We hope to have the C\*STERODID trial running across New Zealand by the end of this year, for more information including a link to our participant video please go to [www.auckland.ac.nz/en/liggins/in-the-community/clinical-studies/clinical-studies-pregnancy/c-steroid-feasibility-study.html](http://www.auckland.ac.nz/en/liggins/in-the-community/clinical-studies/clinical-studies-pregnancy/c-steroid-feasibility-study.html) or email the team at [csteroid@auckland.ac.nz](mailto:csteroid@auckland.ac.nz)



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