

October, 2022



Kia ora

Welcome to our October update

Our new logo embraces the new Te Reo word and meaning for cerebral palsy: Hōkai Nukurangi – to achieve what is important to you, based on birds adapting to different environments. Each individual and each individual whānau have different wants, needs and goals for their pepi for a good, happy life. Our PĒPI ARC Hub with whānau supporting whānau aims to support and nurture each whānau's journey.

The PĒPI ARC team have been busy preparing for our ethics and Research Advisory Group - Māori submission. This includes developing consent forms, questionnaires, interview questions and our study protocol. We are excited to report, this is with our Steering Group for review.

We had wonderful engagement from 8 whānau who shared their experiences and journey from the Wellington NICU to local services. Thank you to the whānau and referring therapists. We always learn so much when we listen to the mahi of those with lived experience. This information and the support of our advisory group continues to help inform our planning and direction.

Thank you for sharing this journey with us. Nga mihi nui.

Whats new

- Our PĒPI ARC logos are designed!
- We have booked our HUB base at Johnsonville starting March 2023
- Alison and Sally ran 8 Whānau Hui to receive feedback about current service delivery for preemie babies
- Meghan welcomed and has met with our Advisory Group for local and regional feedback
- PĒPI ARC protocol is with the Steering Group for research direction

Next Steps

- Ethics submission
- Research Advisory Group-Māori (RAG-M) submission
- Development of information resources
- PĒPI ARC staff are completing Advanced General Movements training
- Gathering feedback on our PĒPI Passport

Feedback

- Let us know if you would like some updates on HINE training, scoring and interpretation
- Let us know what you would like to be included in our information packages
- PEPIARC@CCDHB.health.nz