CHYLD

CHILDREN WITH HYPOGLYCAEMIA AND THEIR LATER DEVELOPMENT

CHYLD Study Update

LIGGINS INSTITUTE
THE UNIVERSITY OF AUCKLAND
NEW ZEALAND
Te Whare Wānanga o Tāmaki Makaurau

Issue 1, December 2011

Thank You to all Friends of the CHYLD Study

"The generosity of spirit displayed by our Friends inspires us to work even harder"

As the year closes, the CHYLD study would like to thank all of its 'Friends': people from many disciplines who generously give their time and expertise to ensure that the study reaches every child it possibly can.

You do this because you believe in the study: its goals, its potential for improvement in child health, and its people. The CHYLD study team deeply appreciates every instance of assistance from our Friends.

Our Friends include paediatricians who go out of their way to examine a child when our team is in town; administrative staff who arrange for us to have rooms and other resources for our assessments; and clinicians and professionals of many disciplines who provide advice, facilitate, or support us with their enthusiasm. If you are reading this Update, you are one of those people.

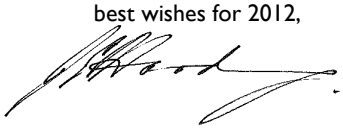
The generosity of spirit displayed by our Friends inspires us to work even harder, to ensure that we conduct our study with rigour to provide the highest quality data, and to produce results that will improve care, health and development of at-risk newborns in the future.

This Update is our attempt to share with you the progress of the study so far. We could not have come this far without your help. I know that I speak for the entire team when I say that your contributions do make a difference for us, for the outcomes of the study, and for children in New Zealand and worldwide.

CHYLD Study Principal Investigator Jane Harding,

Professor of Neonatology, Deputy Vice-Chancellor (Research), University of Auckland

Many thanks and best wishes for 2012,



Jane Harding

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CHYLD Study Finds Its Stride

"We hope that the outcomes of this study will inform best clinical care of at-risk newborns in the future."

In 2011, the CHYLD study accelerated from a walk to a sprint, with assessments of 2 year olds increasing from 7 children per month in the first quarter, to 20 children per month in the final quarter.

We are also looking ahead at a very busy 2012, as this rate will continue until the last of our cohort turn 2 years old at the end of the year. Growth in the assessment rate has driven growth in the team, and we have recruited and trained 15 new staff members to assist with performing assessments, project management, and data management.

In addition to assessing our cohort at 2 years of age, the first of our children began turning four-and-a-half (4.5) years old in June 2011. We have launched an entirely new assessment for our 4.5 year olds, and have approximately 5 children to see per month until mid-2013, when numbers will begin to increase.

The CHYLD study is an excellent study to work on and has been fortunate to recruit a team of researchers and professionals who are fully dedicated to assessing the health outcomes of these children.

Hypoglycaemia affects between 5 and 15% of all newborns, and has long been known to be a risk factor for adverse development.

Neurodevelopmental consequences of neonatal hypoglycaemia include reduced IQ, motor delay, seizures and epilepsy, visual problems and memory impairments. We hope that the outcomes of this study will inform best clinical care of at-risk newborns in the future.

The CHYLD study team at our November 2011 meeting.

The CHYLD Study Cohort: Newborns at Risk

Nurse Practitioner and CHYLD Steering Group member Deborah Harris with a CHYLD study baby in the NICU at Waikato Hospital

Children with Hypoglycaemia and their Later Development (CHYLD) is a follow-up study of a group of children who were identified as being at risk of neonatal hypoglycaemia.

These children were recruited into two studies run in Newborn Services at Waikato Hospital, and most had continuous monitoring of their glucose concentrations in the first few days after birth.

The first study, BABIES, observed the blood glucose levels of 100 babies admitted into the Newborn Intensive Care Unit between Dec 2006 and Feb 2009.

The second study, Sugar Babies, was a randomised controlled trial of dextrose gel as a treatment for neonatal hypoglycaemia, and recruited 514 babies between Nov 2008 and Nov 2010. Not all of these babies were admitted to the NICU, but all had risk factors for neonatal hypoglycaemia including preterm birth (35-37 weeks), being small or large for gestational age, or being the infant of a diabetic mother.

The CHYLD study began assessing 2 year olds in July 2010. At this time 65 of the BABIES cohort were already too old; these children are now being assessed at 4.5 years of age.

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Follow-up of 2 Year Olds Finds Huge Support from Families

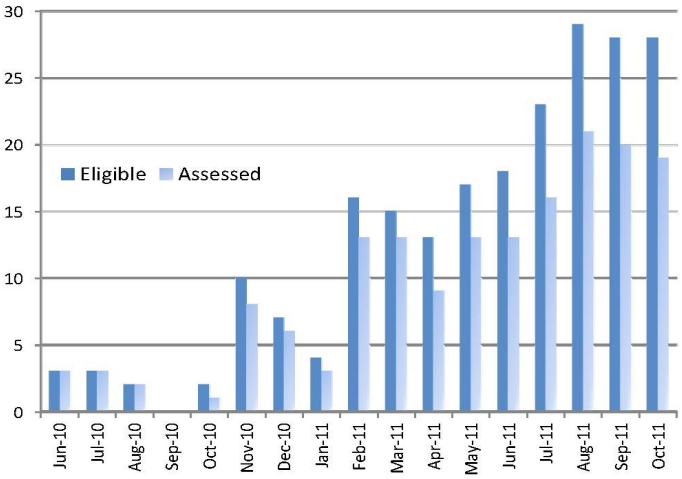
Over the last 18 months, the CHYLD study assessment team, led by Senior Research Nurse Coordinator Coila Bevan, has been tracing families all over the country, and occasionally beyond, to assess the development of their children at two years of age.

Finding families is a constant challenge for Coila and her team, who hunt through clinical records and national databases, and sometimes phone more than eight people or physically visit multiple households, in order to locate the children who took part in the original studies as newborns *[Story below]*.

However, these efforts have proved an enormous success, with the majority of families responding positively to the study. Our follow-up rate of eligible children since the study was launched in July 2010 is over 75% , thanks to the dedication of both the CHYLD team and the participating families to the well-being of their children. By the end of 2011, we will have assessed almost 200 children. We have over 280 more children turning 2 next year.

At two years old children are demonstrating emerging language, motor, and social-emotional skills that might be affected by neonatal hypoglycaemia, and that can be assessed using well validated standardised measures.

The assessment includes paediatric and vision exams, psychometric testing, parent questionnaires of child behaviour, and testing of cognitive abilities grouped as 'executive function' *[Story below]*.



Assessment of eligible 2 year olds from study launch to October 2011.

Coila Bevan, Senior Research Nurse and Assessment Coordinator

"...follow-up rate of eligible children since the study was launched in July 2010 is over 75% , thanks to the dedication of both the CHYLD team and the participating families..."

Assessment of 2 Year Olds

Our assessments of 2 year old children include a paediatric exam, vision exam, developmental assessment, and parent questionnaires of child behaviour.

The paediatric exam includes a basic neurological exam, assessment of physical growth and health, a brief consultation with the parent or caregiver regarding medical history, and a test of motor function .

The vision exam includes a standardised test using Teller or Cardiff cards, and tests for squint and red reflex. The optometrist also tests the child's ability to see motion using a computer-based test of moving dots.

The developmental assessment includes the standardised Bayley Scales of Infant and Toddler Development (Bayley-III), which assesses cognitive, language and motor domains. There is a battery of 4 short tasks to test executive function, which allows us to plan and control our behaviour.

There are 2 standardised parent questionnaires, the Bayley-III and the Brief-P, which assess social and emotional behaviour and executive function. We ask parents to fill out a CHYLD study-specific questionnaire to collect information on the child's home, family, socio-economic, and medical background.

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CHYLD Study Update

The 4.5 Year Follow-up Study: A New Assessment

Jenny Rogers, Research Nurse for the 4.5 year follow-up study

In June 2011, the first children recruited for the BABIES study (p. 2) turned four-and-a-half years old. The CHYLD study team was ready with a new assessment tailored to capture their cognitive, behavioural, visual, motor skill, and neurological development, in the crucial period before the child enters school.

Most of the children from the BABIES study, who all turn 4.5 years old between June 2011 and August 2013, were not assessed at 2 years of age because they were already too old when the study was launched.

"It was very important to us to capture the developmental outcomes of these children, who we were not able to see at 2 years old. We are very grateful for the NIH funding *[Story below]* that has allowed us to do this for them at 4.5 years of age, before they enter school" says Principal Investigator Jane Harding.

So far we have seen 12 children at 4.5 years of age, and have a 100% follow-up rate, with no families lost or declining to participate. This requires great persistence from the study Research Nurse, Jenny Rogers, who traces the families and travels extensively with her team to perform assessments of the study children.

Assessment of 4.5 Year Olds

"It was very important to us to capture the developmental outcomes of these children [now 4.5 years old], who we were not able to see at 2 years old."

Our assessments of 4.5 year old children include a paediatric exam, vision exam, developmental assessment, and parent questionnaires of child behaviour.

The paediatric exam includes a basic neurological exam, assessment of physical growth and health, a brief consultation with the parent or caregiver regarding medical history, and a standardised test of motor function.

The vision exam includes standardised tests for visual acuity, and tests for squint and red reflex. The optometrist also tests the child's ability to see motion using a computer-based test of moving dots.

The developmental assessment includes two standardised tests: the Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III) and the Beery-Buktenica Developmental Test of Visual-Motor Integration (BEERY VMI). There is a battery of four short tasks to test executive function, which allows us to plan and control our behaviour, and three short tests for auditory processing.

There are also four standardised parent questionnaires, which are used to assess the child's social and emotional behaviour, abilities and difficulties, and executive function.

US Grant Funds 4.5 Year Follow-up

The CHYLD Study and Principal Investigator Jane Harding have been awarded a prestigious grant by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, one of 21 institutes which make up the United States National Institutes of Health (NIH).

It is very rare for researchers outside the US to win NIH funding. As Jane explains, "You have to have an argument that says we can contribute in a way that North American investigators can't."

"The NIH recognises that we can do this study better and faster than anyone in the US because we have a population already willing to participate in the study and available for follow-up."

The NIH award will fund the CHYLD study for five years, enabling our team of investigators to follow the development of the full cohort of children at 4.5 years of age, in addition to ongoing assessments of 2 year olds.

The outcomes of the study will inform clinical practice internationally, in addition to improving care of newborns within New Zealand.

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The CHYLD Study Steering Group

Along with our Principal Investigator, Professor Jane Harding, the goals and methods of the CHYLD study are driven by our Steering Group. The group is composed of researchers from five different disciplines, who work together to ensure that the aspects of child development relevant to the study are accurately assessed.

Dr Trecia Wouldes, *PhD*
Dept of Psychological Medicine, University of Auckland

Ms Deborah Harris, *MNurs*
Neonatal Nurse Practitioner, Waikato Hospital
PhD Candidate, Liggins Institute

Dr Jane Alsweiler, *MBChB, PhD (Paediatrics)*
Dept of Paediatrics, University of Auckland
Noenatologist, Auckland City Hospital

Professor J. Geoffrey Chase, *PhD*
Dept of Mechanical Engineering, University of Canterbury

Dr Ben Thompson, *PhD*
Dept of Optometry and Vision Science, University of Auckland

The CHYLD Study Doctoral Candidates

The research objectives of the CHYLD Study, and the wealth of information collected, make it an excellent opportunity for trained clinicians and scientists wanting to pursue a PhD. We are lucky to have three excellent PhD candidates, who have made outstanding contributions to its design, development, and progress.

Judith Ansell is an educational psychologist with a special interest in the interplay between cognitive and behavioural development, especially in the area of Executive Function. Judith is analysing these outcomes among our cohort at 2 years of age.

Sandy Yu (left) and Judith Ansell celebrating the first 46 assessments of 2 year olds.

Sandy Yu is an optometrist with a special interest in paediatric optometry. She is part of the Visual Neuroscience Laboratory within the Department of Optometry and Vision Science. Sandy is investigating visual function and global motion perception/detection among our 2 year olds.

Matt Signal is a biomedical engineer with a special interest in the glucose-insulin regulatory system. He is investigating how to improve diagnosis of hypoglycaemia using continuous glucose monitoring devices. Matt received a new investigator award at the Perinatal Society of New Zealand annual conference in 2010.

Matt Signal, a bio-engineer and one of the CHYLD study's outstanding PhD candidates

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2-6 Park Avenue, Grafton, Auckland
Postal address: CHYLD Study, Liggins Institute, University of Auckland, Private Bag 92019, Auckland 1142
Phone: (09) 373 7599
www.liggins.auckland.ac.nz

Principal Investigator, Distinguished Professor Jane Harding

CHYLD Study Principal Investigator Jane Harding,

Professor of Neonatology, Deputy Vice-Chancellor (Research), University of Auckland

Leading the CHYLD study is our Principal Investigator, Professor Jane Harding. In this role, Jane bears ultimate responsibility for the academic direction, operation, and outcomes of the study, and works closely with the steering group and project management team to keep the study on track.

With over 20 years as a principal investigator in the field of neonatal research, and over 230 peer-reviewed publications, Jane brings an expertise that is the foundation of the project.

Jane runs her research program as part of the Fetal and Neonatal Physiology Group at the Liggins Institute, and is also the Deputy Vice-Chancellor of Research for the University of Auckland.

She has graduated more than a dozen clinician PhD students by involving them in projects like the CHYLD study, which allow them to design and perform assessments, manage large parts of a clinical study, and publish their results in international medical journals.

Jane was recently acknowledged as one of only 18 Distinguished Professors of the University of Auckland, a title that recognises academic researchers who have achieved international eminence of the highest order in their field of research and study.

Recognised as a New Zealander of the Year in 2004, Jane was also more recently featured in the Listener magazine *[Link below]*.

http://www.listener.co.nz/commentary/jane-harding-interview/

The CHYLD Study Project Management Team

Dr Janine Paynter, Data Manager/ Statistician

Ellen Campbell, CHYLD Study Coordinator

While the academic agenda of the CHYLD study is managed by the principal investigator, steering group and PhD candidates, the logistics of assessing hundreds of children and handling the abundance of resulting data are in the hands of the project management team.

With Jane Harding at the helm, the project management team consists of Senior Research Nurse and Assessment Coordinator Coila Bevan, Data Manager/Statistician Dr Janine Paynter, and Study Coordinator Ellen Campbell.

Coila *[photo p.3]* has worked with Jane for over 15 years on a number of clinical trials and follow-up studies. For the CHYLD study, Coila was involved in launching the 2 year follow-up and manages the assessment staff and schedule, and everything related to tracing and communicating with study families.

Janine joined the CHYLD team in May 2011 with the mammoth task of building the study database from thousands of pages of clinical records and study paperwork. Janine also manages the systems that ensure data is complete, accurate, and secure, and advises researchers in the group on statistical analyses for publication. Janine is advised by Biostatistician Dr Greg Gamble and manages a team of research assistants for data clerking and entry.

Ellen Campbell joined the CHYLD team in August 2011, and is facilitating start-up of the 4.5 year study and transition to the NIH award. She also manages recruitment and induction of staff, and internal and external communications for the project.

From the CHYLD study to our Friends, Thank you!

Merry Christmas and Best Wishes for 2012!