2014/2015 Summer Studentship Project Application Form Send to: Research Office, University of Otago Christchurch, PO Box 4345, Christchurch, by 5pm on 4 July 2014 Supervisor Information (First named supervisor will be the contact): Supervisor's Name(s): Prof Brian Darlow, A/Prof John Horwood, Dr Maggie Meeks Department: Paediatrics Institution: UOC Phone: 03 3640747 E-mail: brian.darlow@otago.ac.nz Mailing Address: Research Category (Choose one category only – to be used for judging the students' presentations): Clinical Laboratory Community x Project Title (20 words MAXIMUM): Very low birthweight young adults: parental assessments of their health and social functioning Project Description:

Very low birthweight infants (birthweight <1500g – VLBW) account for only 1-2% of live births but between 50%-75% of the work load of neonatal intensive care units (NICUs). Survival for this group is now >90% but what is most important for individuals, their families and society, is the quality of that survival in the longer term. In 1986 we enrolled all New Zealand VLBW infants, who were cared for in NICUs, in a prospective study. At 7-8 years of age 5% of survivors had severe disability, 5% had moderate disability and 15 % had mild disability. Overseas studies of former VLBW infants in young adulthood have suggested increased risks of physical and health problems, educational underachievement and poorer social functioning than their peers. When the cohort were 22-23 years, 230 (71% survivors) were retraced and 69 controls, born at term in 1986, were recruited and administered a questionnaire on measures of health, social functioning and quality of life. Despite poorer outcomes than controls on a number of measures, the VLBW cohort rated their quality of life no differently (*Pediatrics* 2013; 132: e1521). At the time of this questionnaire both groups gave consent for their parents to be contacted to seek their willingness to answer a similar questionnaire about their VLBW offspring.

<u>Aims:</u> To trace and contact parents of the VLBW cohort and controls, administer a questionnaire on their assessments of their son/daughter's health, social functioning and quality of life, and to compare these responses to the self-reports.

Methods: Contact details for parents are in our database but will need updating. Parents will be contacted in writing and/or by telephone, the purpose of the study explained and written consent for their participation sought. The questionnaire is based on several standardized assessment tools supplemented by custom written survey items previously used by the Christchurch Health and Development Study. Practice sessions will be required to administer this successfully at a telephone interview. Parents will also be asked questions about their experiences as a parent of a VLBW child/adolescent/young adult. Interviews will be scored and entered into an electronic database and the results compared with the self-responses of the VLBW cohort.

<u>Significance</u>: We envisage that up to 50 parents should be able to be contacted and asked the questionnaire in the time scale of the studentship, so we consider this a pilot study only that will be underpowered to detect significant differences between parental and VLBW young adult responses. Nevertheless this pilot will be an important step to refine our procedures to be able to contact and obtain responses from the full set of parents. And the results should indicate whether New Zealand parents judge their offspring's quality of life at a lower level than self-reports as has been reported from a number of overseas studies.

In an HRC funded study our group is currently assessing both the VLBW cohort and controls on a range of medical and psychological investigations during a two day stay in Christchurch. Hence the student will be part of a dynamic team and will be exposed to the complexities and rewards of such research as well as being fully supported in their project.