



UNIVERSITY
OF MANITOBA

Research Study of Children with Phenylketonuria (PKU)

Principal Investigator - Dr. Cheryl Rockman-Greenberg

What is the purpose of this study?

To evaluate brain development, intelligence, body growth, and blood phenylalanine levels in young children who are taking Kuvan (study drug) and who follow a low phenylalanine PKU diet. The study will also evaluate if Kuvan is safe to take for a very long time.

Who can participate?

Children with PKU ages 0-6 years, as this is a critical time for brain development.

What is involved?

Part 1: visits over a four-week period that include:

- Monitoring of blood pressure, pulse, and temperature
- Blood and urine samples
- Height, weight and measurement of head size
- Taking the drug daily and filling out a daily diary
- One ECG at first visit
- Ask questions of child's health and any side effects to taking Kuvan
- At consultation with a dietician at each visit

Part 2: may happen over a seven-year period with visits that include:

- Brain development and intelligence tests that are age appropriate at six-month intervals.

For more information on the study and to participate, email Mandi Siddiqui, Study Coordinator for Dr. Greenberg at msiddiqui@mich.ca