



PKU Clinic Update

Children's Memorial Hospital

Clinic Staff

- Nutritionists:
 - Heather Bausell
 - Maryam Naziri
 - Rhoda Livermore
- Clinic Coordinator/Genetic Counselor
 - Andrea Paras
- Social Workers
 - Hazel Vespa
 - Lauren Leviton

Clinic Staff

- Research Coordinators
 - Rachel Katz
 - Paul Kogut
 - Charlotte Dodsworth
 - Clare Edano
- Advanced Practice Nurse
 - Shanna Widera

Clinical Trials in Progress

- PEG-PAL
- Kuvan
 - PKU-015: Long term study of safety and effect on neurocognitive outcome in patients under 6 years
 - PKU-016: Effect of Kuvan on symptoms of ADHD, depression and anxiety in patients 8 years and older
 - PACT PKU – Single day study of adults off treatment
scheduled in early January
 - PKUDOS



Clinical Trials in Progress

- IBEM-IS: Registry for patients with all newborn screening disorders including PKU
- Home Phe Monitor : Delayed – studies will probably begin in 2012

PKU Clinic CMH

- One PKU patient completed training in Peerwise Program at CMH – will now serve as a peer mentor for patients with PKU
- Study of growth and weight in PKU recently completed, data now being analyzed