

## May 2010 Current CRN Research Commitments:

**Jess Thoene, MD**, Univ. of Michigan, Ann Arbor, “Tissue Repository for Cystinosis” Grant awarded: 30 August 2005, interrupted immediately by hurricane Katrina. New start date: 21 Nov. 2006 – ongoing. Total award: \$26,206.00

**Elena Levtchenko, MD, PhD** Univ. Medical Center Nijmegen, The Netherlands, “Study of ATP metabolism in human cystinotic proximal tubular cells and in humans with cystinosis in vivo” Grant awarded: 11 September 2006 for 1 year, Jan. 2007 thru Dec. 2007.

Total award: \$68,090.00. A “Final report” for this study was received 5 February 2009. However, an email from Dr. Levtchenko indicated that the “*In vivo* part of this project is not finished yet due to the technical difficulties with the MRS apparatus, but we have good hope that the problem will be solved and this part of the study will be finished in 2009”. CRN acknowledged receipt of this report, but has not accepted it as a “final” report. Dr. Levtchenko is now associated with the Department of Pediatric Nephrology, University Hospital, Leuven, Belgium.

**Catherine Tuleu, PhD** Univ. of London, School of Pharmacy (other names on grant: **Ken Nischal**, Olufemi Rabiou, Rajnish Sekhri, Wm Van’t Hoff and **Bola Lawal**) “Development of cysteamine in situ gelling system for the topical treatment of corneal crystals in cystinosis”, Agreement signed 24 Oct. 2006; Grant awarded January 2007 for 3 years, 1 Mar 2007 – Feb. 2010.

**Leticia Belmont, M.D.**, Unidad de Genetica de la Nutrician, Instituto Nacional de Pediatria, Mexico. “Determination of Intraleucocitary Cystine by High Performance Liquid Chromatography (HPLC) in Patients with Cystinosis”. Grant Awarded: 5 November 2008 for 1 year (Fall ’08 – Fall ’09)

Total award: \$31,972.00.

**Henk J. Blom, M.D., M.M.C. Wamelink, and E. Levtchenko**, VU University Medical Center, Amsterdam, The Netherlands: “Newborn Screening of Cystinosis”.

Grant Awarded: 5 November 2008 for 18 months (Fall 2008 – Spring 2010). Total Award: 45,000 euros (approximately \$67,500.00 -- approximately 60,818.71 USD, as calculated 3-2010).

**Francisco Emma, M.D. and Anna Taranta, Ph.D.**, Bambino Gesu Children’s Hospital and Research Institute, Rome, Italy: “Functional Characterization of Cystinosin-LKG”. Grant Awarded: 5 November 2008 for 2 years (January 2009 – December 2010). Total Award: \$114,480.00.

**Jess Thoene, M.D.** University of Michigan, Ann Arbor, MI, “Feasibility of Cystinosin Replacement Therapy in Cystinosis”, Grant awarded 9-25-09 for two years (9-1-09 to 8-31-11) Total Award: \$165,732.00.

**Dr. Ewa Elenberg**, Texas Children's Hospital, Houston, TX “Quality of Life in Cystinosis Patients”, Grant awarded 9-25-09 for 1 year (10-1-09 to 9-30-10) Total award: \$21,000.00.

**Dr. Paul Goodyer**, Montreal Children's Hospital, Montreal, Canada, and **Dr. Rick Kaskel**, Children's Hospital at Montefiore, Bronx, NY. "Proposal for a North American Cystinosis Research Platform". One year grant of \$36,000.00 awarded for development.