NICHD SCID Newborn Screening Trial

- NICHD has negotiated a 12-month extension to a contract with Health Research Incorporated of Rensselaer, NY, to continue operations of "Novel Technologies in Newborn Screening"
- One year, ~ $1.1 million contract awarded on April 15, 2010 to PI, Kenneth Pass, PhD.
- The extension will permit HRI and collaborators to provide evidence and feasibility of technologies related to Severe Combined Immunodeficiency (SCID) in the environment of newborn screening.

Participating States and Organizations

State	Number of Babies	Tests	Other Participants
California	~500,000	TREC	PerkinElmer Jeffrey Modell Foundation
Massachusetts (possibly others)	~70,000 – 80,000	TREC/ some Luminex	University of Massachusetts Medical School
New York	~40,000	TREC/ some Luminex	

Data Management	SCID Samples	Purpose
NBSTRN - negotiating adaptation of the Region 4 Stork (R4S) web-based program at the Mayo College of Medicine	New database unit being developed for SCID testing results	NIH resource for SCID research community

SCID Trial Timeline

1st Quarter

- Establish contracts
- Database design
- Initiation of testing

2nd Quarter

- Begin testing
- Data upload to central site

3rd Quarter

- Continued testing and reporting
- Meeting of all participants
- Review of data
- Revise protocols and reporting as needed

4th Quarter

- Complete testing
- Ensure data is uploaded to the central database
- Review and analyze data
- Prepare report for NIH

Current NICHD NBS Initiatives

- **Natural History of Disorders Identifiable by Newborn Screening (R01)**
  - RFA-HD-10-019
  - Deadline August 3, 2010
  - Solicits applications from institutions/ organizations that propose to develop a comprehensive understanding of the natural history of disorders that are currently identified by NBS or could potentially benefit from early identification by newborn screening.
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- **Novel Technologies in Newborn Screening - PAR**
  - Solicitation Number: NIH-NICHD-CDBPM-10-15-PS
  - Deadline June 3, 2010
  - The purpose of this contract is to develop multiplexed assays that can be automated and utilized in a high throughput environment for newborn screening