



# NBS for SCID: State Status

## *NBSTRN Update*



**Michael Watson**

- ◆ **NICHD subcontract to New York State primarily funds per baby costs of screening to:**
    - **New York (79,511)**
    - **California (~200,000)**
    - **Louisiana via Wisconsin (16,683)**
    - **Puerto Rico via Massachusetts (~16,000)**
  - ◆ **NBSTRN Coordinating Center supports**
    - **meetings of experts**
    - **coordination of NBSTRN resources needed in project**
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- ◆ **Infrastructure to support collaborative approach to laboratory data sharing in pilot studies**
  - ◆ **Resources and infrastructure to develop clinical data sets for diagnosis, treatment, and monitoring**
    - **Electronic language standardization**
  - ◆ **IT and informatics to support point-of-care data collection**
  - ◆ **ACT Sheets to support primary care providers role in diagnosis and follow-up of screen positive individuals**
  - ◆ **Directory of clinical specialists in pediatric immunodeficiencies and T-cell lymphopenias**
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## Michele Caggana (Chair)

Member	Institution/Affiliation	Area of Expertise	NBSTRN Focus
Roshini Abraham, PhD	Mayo Clinic	Immunology	Pilot, Screening Database
Jennifer Puck, MD	UCSF	Immunology	Pilot, Data Set Generation
R. Rodkney Howell, MD	University of Miami	Pediatrics	SACHDNC, NBS, Policy
Vincent Bonagura, MD	Long Island Jewish Medical Center	Immunology	Data Set Generation
Dieter Matern, MD	Mayo Clinic	Biochemical Genetics	Pilot, Screening Database
Sean McGhee, MD	UCLA	Immunology	Diagnosis, LTFU
Ricardo Sorenson, MD	Children's Hospital/New Orleans	Immunology	Data Set Generation
Fred Lorey, PhD	CA Dept of Public Health	Newborn Screening	Pilot, NBS
Mei Baker, PhD	University of Wisconsin	Newborn Screening	Pilot, NBS
Anne Comeau, PHD	University of MA Medical School	Newborn Screening	Pilot, NBS

- ◆ **R4S (Region 4 Laboratory Performance Project)**
    - **Administratively directed by Dr. Piero Rinaldo at the Mayo Clinic**
    - **SCID databases curated by Drs. Fred Lorey and Roshini Abraham**
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## SCID COLLABORATIVE PROJECT



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# SCID

### CURRENT DATA POSTED BY YOUR NEWBORN SCREENING LABORATORY

[Cutoff Values](#)

[Normal Percentiles](#)

[True Positives](#)

[Performance Metrics](#)

[Last Update](#)

### COMPARE YOUR LABORATORY DATA WITH OTHER PARTICIPANTS

[Cutoff Values Comparison](#)

[Percentiles Comparison](#)

[Performance Metrics Comparison](#)

[Disease Range](#)

[Disease Range \(MoM\)](#)

[Analyte Comparison](#)

[Profile Comparison](#)

### CUMULATIVE PROJECT DATA

[Participant Profile](#)

Participant profile summary of all responses

[Score Cards](#)

Tabular summary of all data (sorted by analyte type)

[Plots by Target Range](#)

Display of evidence-based and actual cutoff distribution for one analyte

- ◆ **Demographics**
  - ◆ **SES**
  - ◆ **Family History**
  - ◆ **Prenatal History**
  - ◆ **Neonatal History**
  - ◆ **Birth Measurements**
  - ◆ **Newborn Screening (Including Hearing)**
  - ◆ **Diagnostic Testing**
  - ◆ **Past Health History**
  - ◆ **Emergency Management**
  - ◆ **Developmental Screening**
  - ◆ **Imaging Studies**
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# Insert disease specific data set

- ◆ **Workgroup being formed to generate data set.**
  - ◆ **Surveying other efforts**
    - **Primary Immune Deficiency Treatment Consortium (PIDTC)**
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# THANKS

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**NBSTRN is funded by contract  
HHSN27520080001C from the  
*Eunice Kennedy Shriver* National  
Institute of Child Health and  
Human Development, National  
Institutes of Health**