Newborn Screening: Current Status of State Newborn Screening Programs

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Brad Therrell, Ph.D.

University of Texas Health Science Center at San Antonio

Newborn Screening and Genetics Resource Center

Austin, Texas

Newborn Screening: Current Status of State Newborn Screening Programs

- Information obtained by contacting all programs and asking for any updated information about program changes since June 2006.
- Report includes only information from those programs wishing to respond and may not contain all changes that have occurred.

Arizona

- 27 disorders screened now - up from 8 in April 2006.
- Cystic fibrosis screening to be added June 30, 2007 for 28.
- Centralized hearing follow-up program added in 2006.

Arkansas

- Oct. 26, 2006 – Expansion approved - Board of Health.
- Now seeking legislative approval for full expansion.
- Fees to increase from $14.83 to $ 89.25 per newborn.
- Plan: Jan. 2008 – Hire additional staff (lab and follow-up)
  March 2008 – Public awareness campaign
  July 2008 – Begin expanded screening

California

- May 1, 2007 – Pilot testing for biotinidase and CF
- July 17, 2007 – Official start date for both conditions

Delaware

- June 30, 2006 - Began Biotinidase deficiency screening.
- October 18, 2006 - Began CF screening using IRT/IRT
- December 1, 2006 - Added carnitine uptake deficiency (CUD)
- Initiating steps to move to web based reporting system

Florida

- Expanded newborn screening began January 2006
- Cystic fibrosis screening is expected to begin July 2007

Georgia

- Began expanded NBS Jan 2007 with fee of $40
- Currently using Voice response and Autofax systems
- Screening for Cystic fibrosis performed via IRT/DNA
- Planning linkage to vital records
- Planning electronic transfer of demographic data from some hospitals

Illinois

- Working on rule change to add CF (IRT/DNA) CF
- Screening expected to begin summer 2007 – 6 mo. limited screening – Fee increase $47 to $59
- $600,000 grant program for CF genetic counseling
- Legislation proposed to add screening for 5 LSDs (Krabbe, Pompe, Gaucher, Niemann Pick, Fabry)
- Bill introduced to support Fragile X NBS

Kansas

- Legislation passed allowing NBS expansion.
- July 2008 – Expansion start date - $800,000 available.
- Coverage of treatment products placed on a sliding scale.

Louisiana

- 2006 – Legislation passed expanding screening to 29 core conditions – all in place except CF
- July 1, 2007 - CF screening scheduled to begin – expected to transition back from Iowa pending move to new building – if not, then Iowa will begin their CF screening

Maine

- CF screening being planned – likely implementation date - January 2008

Maryland

- June 2006 – CF screening added (IRT/IRT)
- New lab instrumentation and software
  - Automated sample preparation for MS/MS, biotinidase and galactosemia
  - New liquid handling system for hemoglobinopathies

Michigan

- Legislation approved to expand NBS program to include 49 of 54 recommended conditions (not GALK, GALE, Tyr II, III).
- October 1, 2007 – Anticipated start for CF.
- Adding a courier service.
- Expanding lab hours to include Saturdays.

Missouri

- January 8, 2007 – CF pilot started – screening expected to begin July 1, 2007 (moving to new bldg about same time).
- CF follow-up contracted to CF centers.
- Biotinidase deficiency screening will be added late 2007 or early 2008.

Montana

- Bill proposed to expand mandatory bloodspot screening from 4 to 28.
- Additional funds requested to expand follow-up and subspecialty services.

Nebraska

- NBS committee recommended changing MS/MS from optional (96% compliance) to mandatory conditional on funding for substantial infrastructure upgrade.
- HHS Director supports change but unable to request additional funding in budget request.

New York

- August 7, 2006 – Added Krabbe Disease – In first 166,000 newborns - 2 high risk, 2 moderate risk identified of 16 referred
- Hemoglobin screening to HPLC (verification by HPLC/IEF)
- Piloted then contracted with specimen delivery service.
- New NBS Program Director and NBS Medical Director

New Hampshire

- Currently screening for 13 conditions (including toxoplasmosis)
- July 1, 2007 – Anticipated start date for 19 additional MS/MS conditions – laboratory negotiations currently underway.

Ohio

- August 30, 2006 – Began screening for cystic fibrosis
- August 30, 2006 – Began screening for carnitine uptake deficiency (CUD)

Oklahoma

- June 5, 2006 - Began screening for MCAD deficiency
- Now offers genetic counseling (certified genetic counselor) for conditions detected through program and sickle trait.
- Additional MS/MS conditions will be staged in and hopefully completed by Dec 2008 with biotinidase after that.

Oregon

- Jan 1, 2007 - New Mexico added to NWRNSP
- CF added for Oregon (2006), New Mexico (2007), and Alaska (2007).
- New laboratory – move in expected August 2007

Rhode Island

- July 1, 2006 – Added 17 conditions to required screening to meet core 29 conditions.

South Carolina

- April 2, 2007 – Began screening for TYR I,II, III
- Contract with Mayo to provide second tier succinylacetone testing.
- Updated cut-offs for IRT and 17-OHP

South Dakota

- Currently - uses in-state laboratory with subcontracts for CF and MS/MS
- June 1, 2007 – Comprehensive contract - Iowa NBS laboratory.
- June 1, 2007 – Will add CF screening.

Texas

- December 6, 2006 - Added 19 MS/MS1 conditions (MRMs).
- January 8, 2007 - Added biotinidase deficiency; not yet CF.
- New reporting format implemented for 27 conditions.
- Updating Voice Response System and considering demographic data entry and results delivery via the internet.

Vermont

- Currently testing for 28 of 29 core conditions
- Undergoing administrative rule changing to include CF, hopefully by the end of 2007.

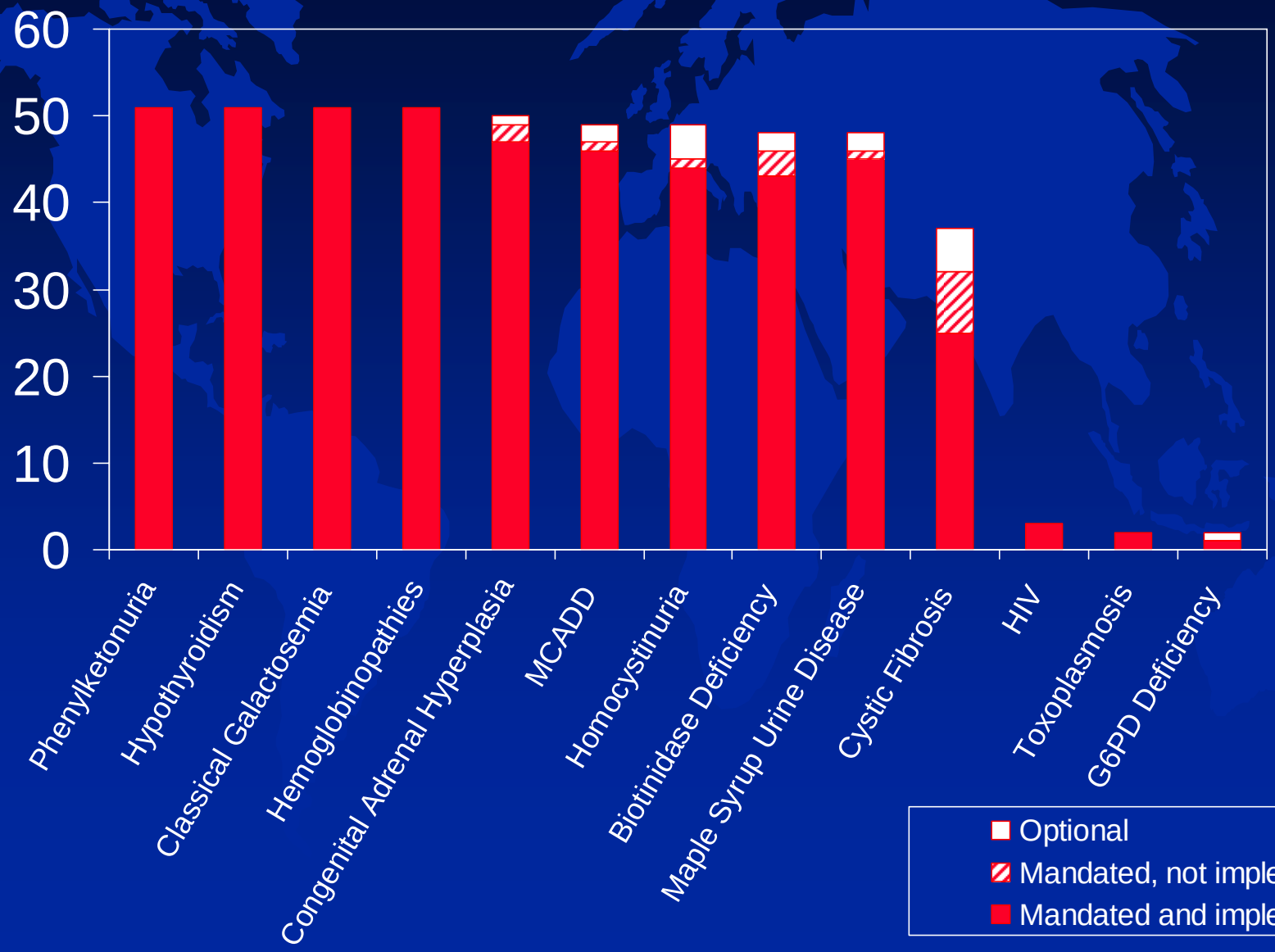
Washington

- Reviewing additional disorders for possible inclusion
- U of Washington has applied for IRB approval for pilot study to detect LSDs.

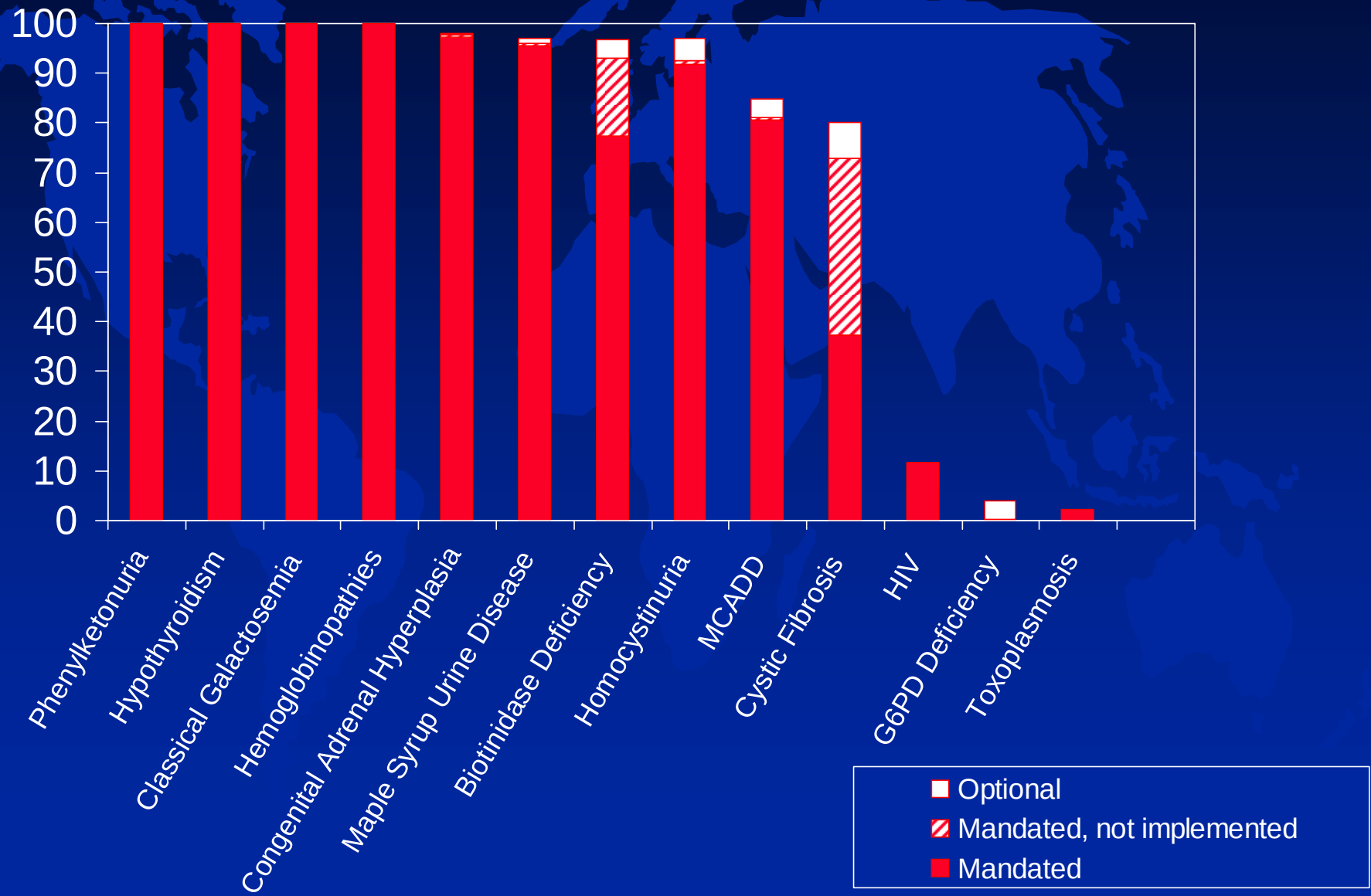
West Virginia

- Legislature mandated expansion from 7 to 29 disorders
- July 1, 2007 – Phase I – CAH, CF, BIO (non-MS/MS)
- July 1, 2008 – Phase II – MS/MS
- Phase II also includes: courier, increased genetic service capacity (counseling, subspecialists, etc.)
- Exploring telemedicine opportunities

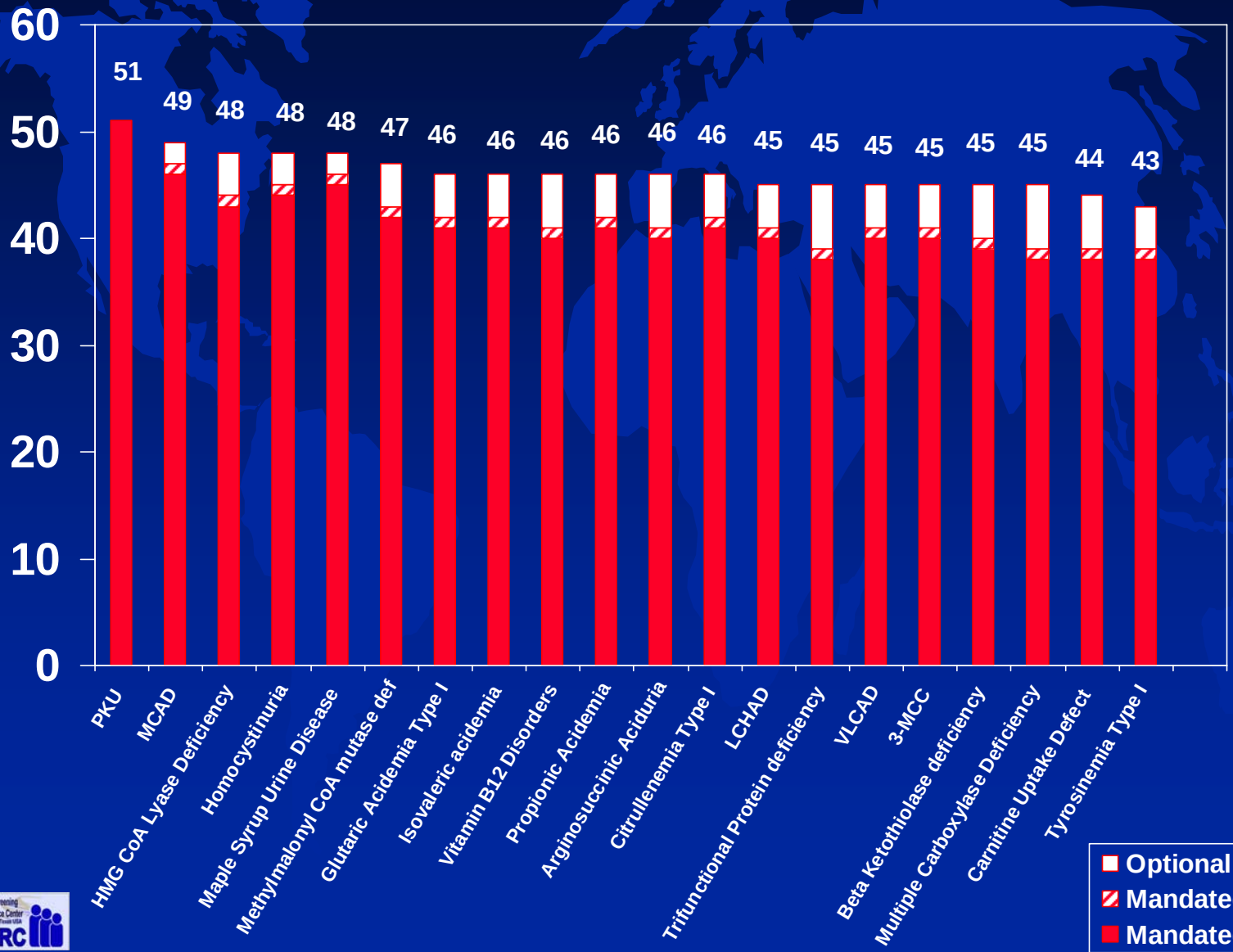
Disorders Screened in United States
May 2007



Percent of Newborns Screened in US May 2007



MS/MS Conditions Screened in United States May 2007



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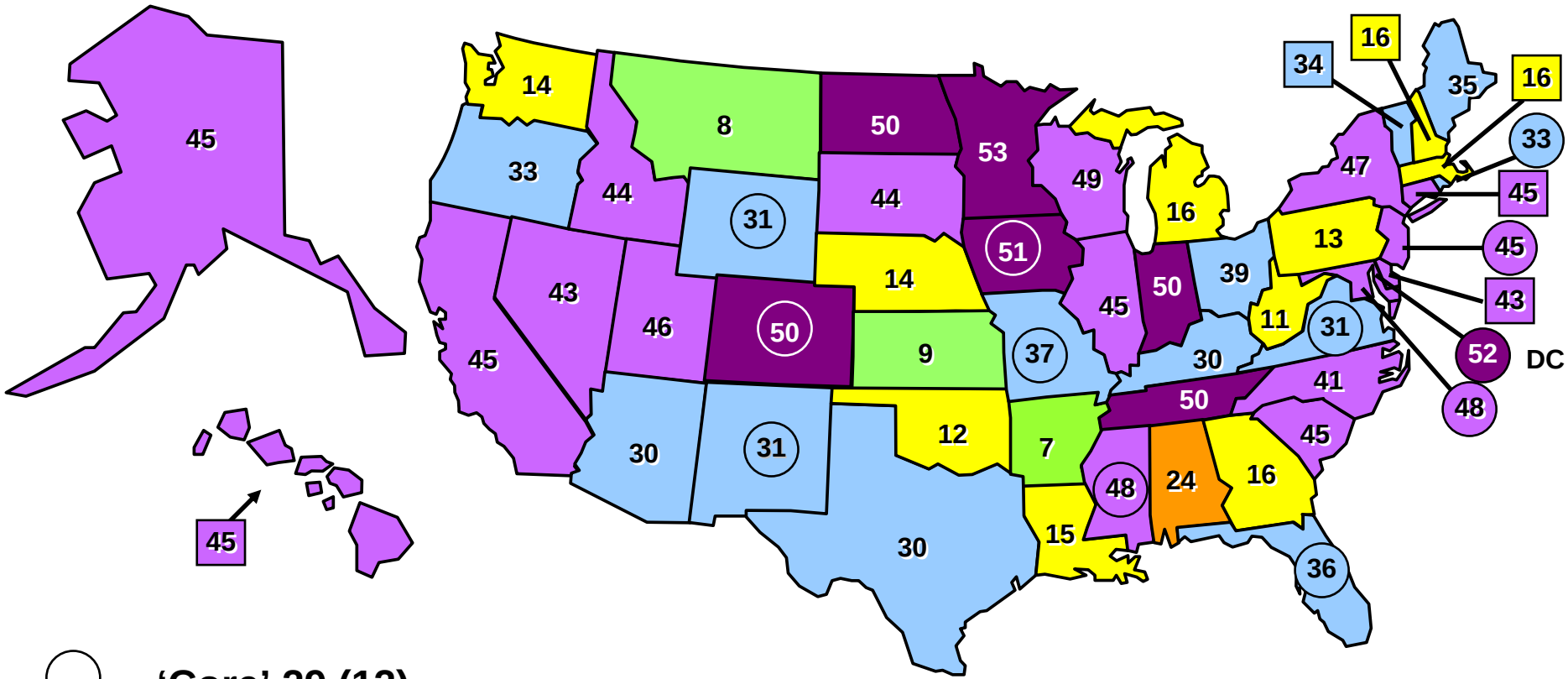
Austin, Texas USA
NNSGRC



‘Core’ 29 (12)

50+ Disorders (7)

40-49 Disorders (17)

30-39 Disorders (13)

20-29 Disorders (1)

10-19 Disorders (10)

<10 Disorders (3)

U.S. Newborn Screening

Conditions Required – June 1, 2006

(Conditions available as an option to selected population are not counted)

Current News/Issues

- CAH kit changes (will require cutoff lowering)
- Filter paper kits (back orders, purchasing, printing)
- CLSI LA4-A5 (filter paper collection standard - rev. 5) to be released soon
- CLSI to begin work on guidelines for screening in transfused infants
- Best protocol for CF screening – IRT/DNA vs. IRT/IRT (carrier detection issues)
- Research considerations - LSDs, SCID, G6PD

A Planning Conference
Utility of Screening for G6PD Deficiency to Prevent Severe Neonatal Hyperbilirubinemia

May 11-12, 2007
Bethesda, MD

Convener: Vinod K. Bhutani (Stanford University)

Aim: To determine whether assessment of G6PD deficiency status in neonates of ethnic/racial background with high prevalence of G6PD deficiency improves the predictive accuracy of a predischarge hour-specific bilirubin measurement in assessing risk of severe neonatal hyperbilirubinemia.

Current Status of G6PD Newborn Screening in the U.S.

- Newborn screening available from Pediatrix Screening
- G6PD screening required in D.C.
- G6PD available in many of the Pediatrix contracted hospitals, particularly in Pennsylvania
- Very little outcome data exist

Newborn Screening for SCID
Working Meeting
May 14-15, 2007
San Francisco, CA

Convener: Jennifer Puck (Univ. Calif. San Francisco)

Aim: To consider how best to organize and implement a newborn screening program for severe combined immunodeficiency (SCID) using dried bloodspots, and to identify possible investigations and collaborations useful in moving the process ahead.

Current Status of SCID Newborn Screening in the U.S.

- Newborn screening test available at UCSF and WI DOH
- Current testing procedure subject to high recall rates
- Research involves both methods and timing of tests (2nd tier – could be benefit to second screen at 1-2 weeks?)
- Newborn screening tests in development at NY DOH, Missouri Research Lab ….
- Wisconsin expected to begin offering limited testing within the year
- Possible screening collaborations identified in:
  WI, NY, CA, MO, MD, MA, ….

http://genes-r-us.uthscsa.edu

http://www2.uthscsa.edu/nnsis/

http://www.marchofdimes.com/peristats/