

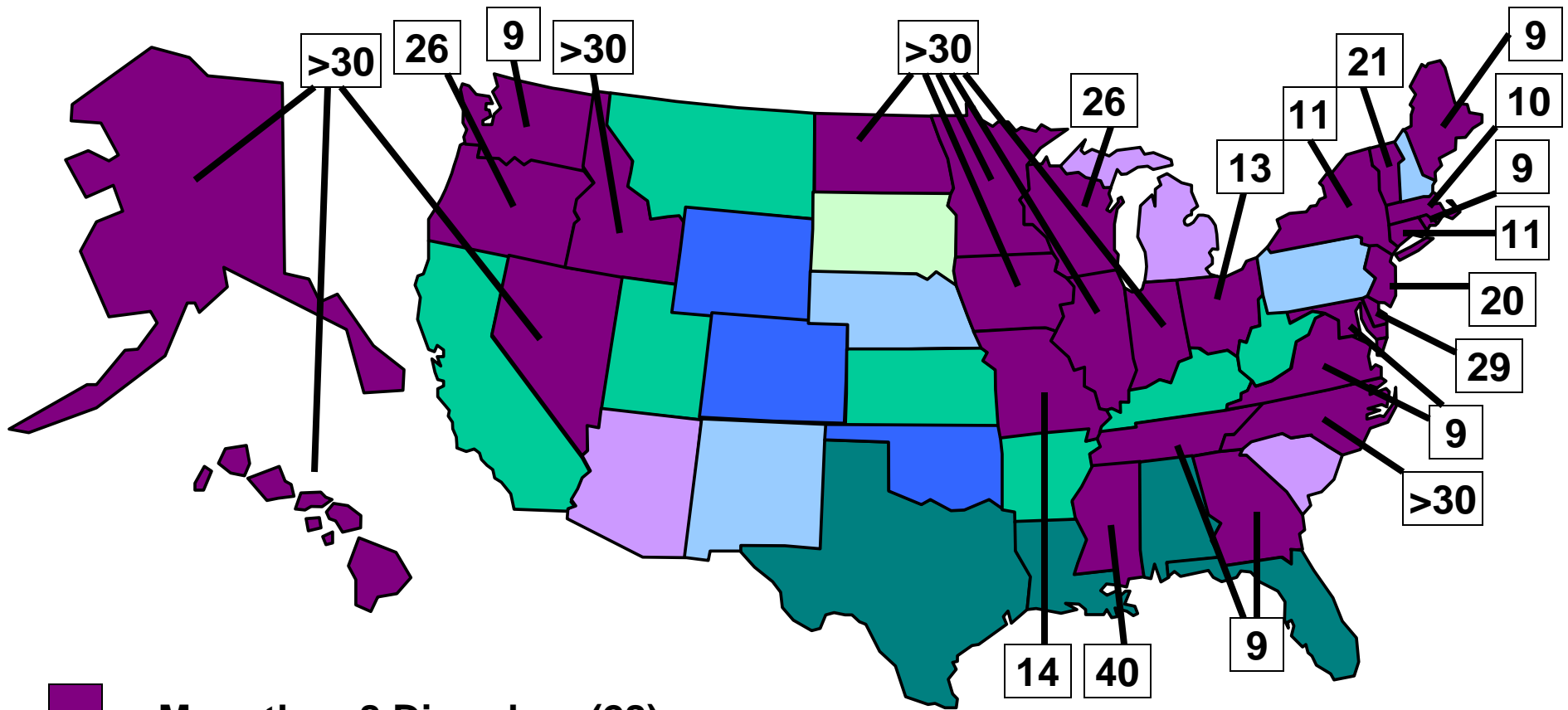
Newborn Screening: Current Status of State Newborn Screening Programs

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Newborn Screening and Genetics Resource Center

Austin, Texas



More than 8 Disorders (28)

8 Disorders (3)

7 Disorders (4)

6 Disorders (4)

5 Disorders (4)

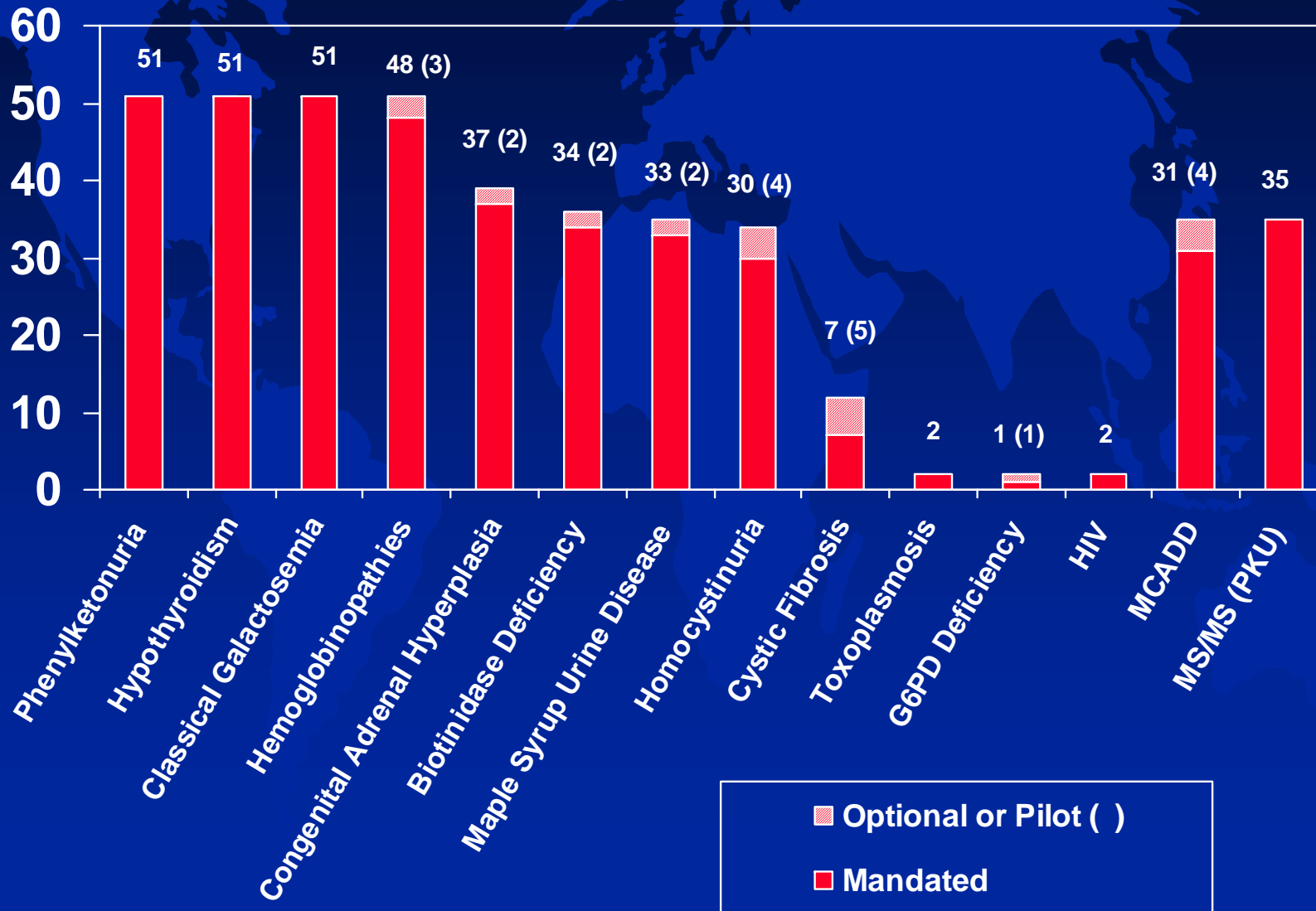
4 Disorders (7)

3 Disorders (1)

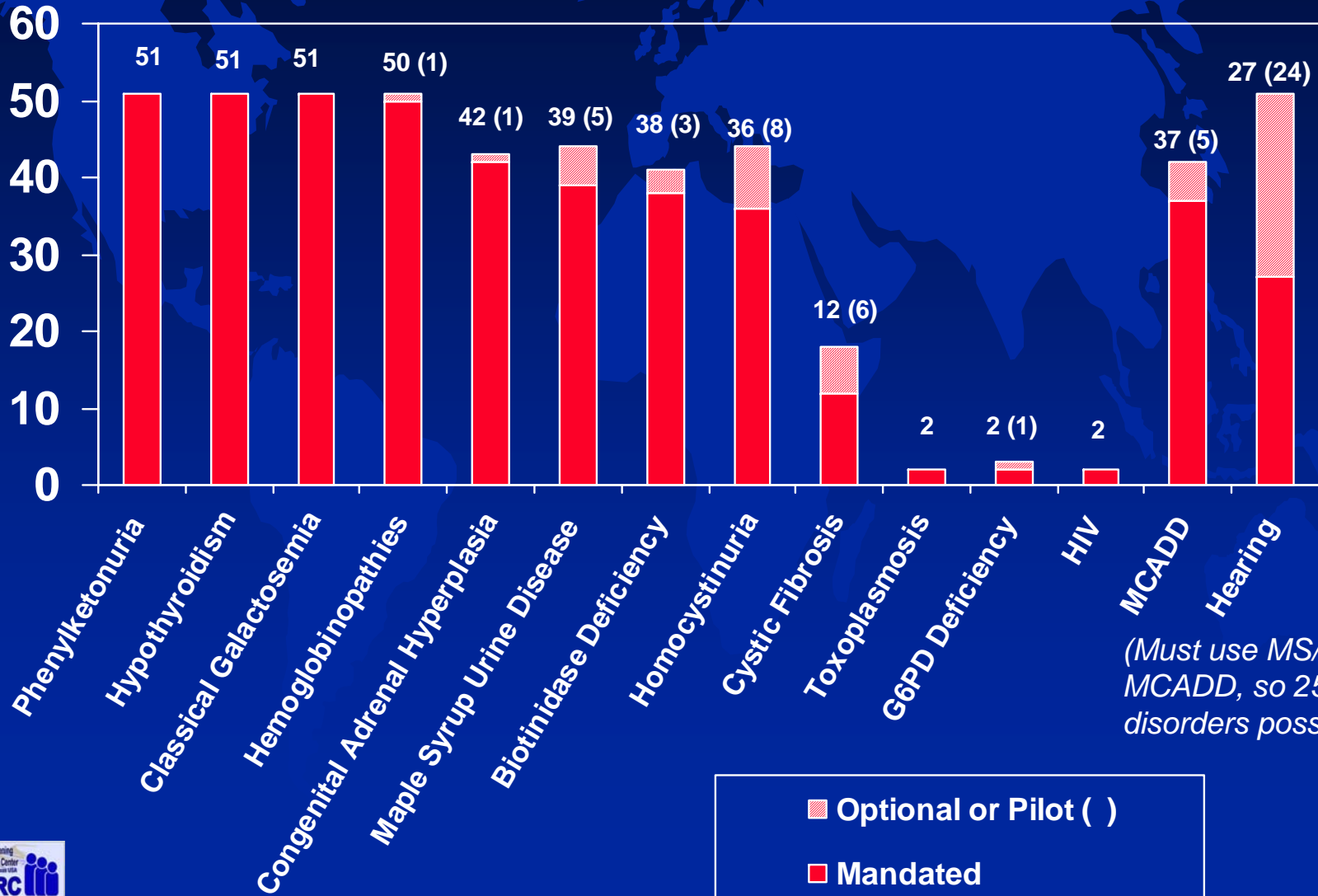
U.S. Newborn Screening

**Mandated Disorders – May 2004 (Note:
Other disorders may be offered but are
not mandated)**

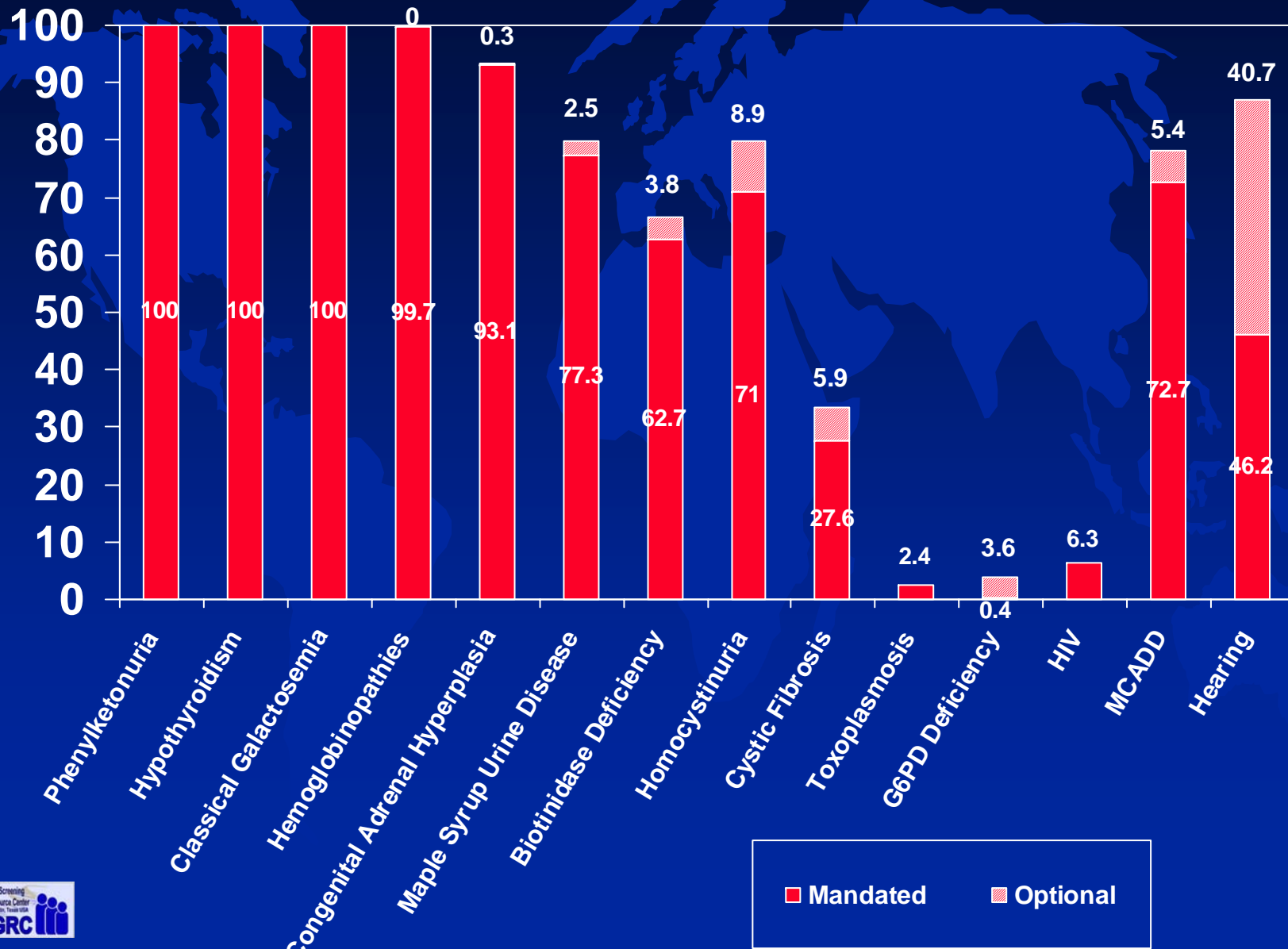
Disorders Screened in United States May 2004



Disorders Screened in United States June 2005



% Newborns Screened in United States June 2005





California



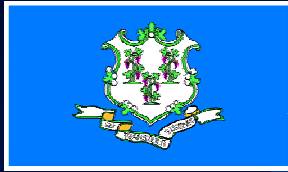
- July 11 - Began mandated screening for all MS/MS conditions and CAH (26 ACMG conditions)
- Not yet mandated – Hearing, Biotinidase, CF



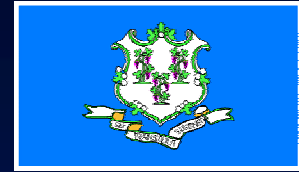
Colorado



- Mandate for full scan MS/MS
- Currently planning implementation
- Anticipated start - Spring 2006



Connecticut



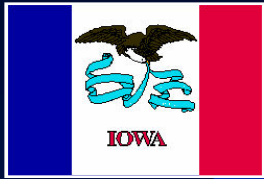
- January 1 – Added 13 more MS/MS conditions (currently all except CF are mandated including hearing screening)
- February 1 – Changed to Astoria-Pacific Tot. GAL kit



Georgia



- January 3 – Added MCAD and PKU, HCY, MSUD, TYR changed to MS/MS
- June 27 – Rules change valid screen to > 24 hours (from 48)
- Currently no cost but developing fee structure



Iowa



- July 18 – Began CF screening
- Lab with courier service operating 24 hrs/7 days per week
- Personnel turnover in follow-up soon to be remedied
- Comprehensive use of fee monies – fee increase in 2006



Kentucky



- March 11 – Mandated addition of CAH, BIO, CF, full scan MS/MS
- Adding CAH in August; MCAD in September; CF and BIO to follow



Michigan



- April 18 – Universal pilot of additional 11 MS/MS conditions (expanded to 29)
- Working towards fee increase to provide comprehensive services and CF



Minnesota



- Mandated CF with anticipated start by Spring 2006
- Moving to new lab facility October 2005



Missouri



- July 1 – Added 20 disorders after 5 month pilot (MS/MS + BIO)
- August 1 – Fee increases from \$25 to \$50
- Bio pilot late 2005; CF pilot 2006



Nebraska



- NB Supreme Court – State can mandate – no dissent option
- Fed. Dist. Court – “Silent Birth” suit dropped - Scientology
- 2nd follow-up staff person added due to increased work.
- Anticipating adding CF and CAH in Jan 2006; expanded MS/MS remains optional (95%) at no additional cost



New Hampshire



- Adv. Comm. Recommended CAH, MCAD, BIO, SCD, CF.
- SB 108 – Changes process to add conditions; changes fee process with dedicated account; defines advisory committee; requires annual report for oversight
- Expansion anticipated in 2006



New Jersey



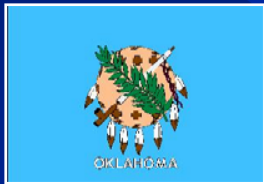
- Currently does not mandate 13 conditions available on MS/MS, but screens for them anyway and reports.
- New Law - Parent required to document receipt of DHSS brochure “Availability of Supplemental Newborn Screening”
- Repeat NBS Screen if prior to 24 hrs. (changed from 48)



North Dakota



- Adding CF early Fall 2005
- Increasing fee from \$36 to \$44
- Continuing to use Iowa NBS laboratory



Oklahoma



- February 2005 – Added CAH and CF



Rhode Island



- Expansion to 29 core disorders anticipated July 2006 (currently only MCAD and amino acids)
- Finishing preparation for Rule change for fee increase
- Monitoring for babies over 6 days of age without a screen



South Dakota



- June 1 – Rules expanded screening to include CAH, BIO, SCD (previously universal pilot), MS/MS (full scan)
- Offering CF (MA contract) as an option
- Updated practitioner manual and distributed



Texas



- Legislation passed to allow for start-up funds and expansion within funds available; clarified that follow-up can be in fee
- Must respond to NNSGRC Review (Oct. 2005) and perform cost analysis (March 2006)
- Anticipated start of expanded testing – Oct. 2006



Utah



- Began full scan MS/MS pilot with ARUP (private lab)
- Allowable fee increased from \$35 to \$65 (currently \$31)
- Anticipates MS/MS screening, CAH and BIO January 2006
- CF not yet included



Virginia



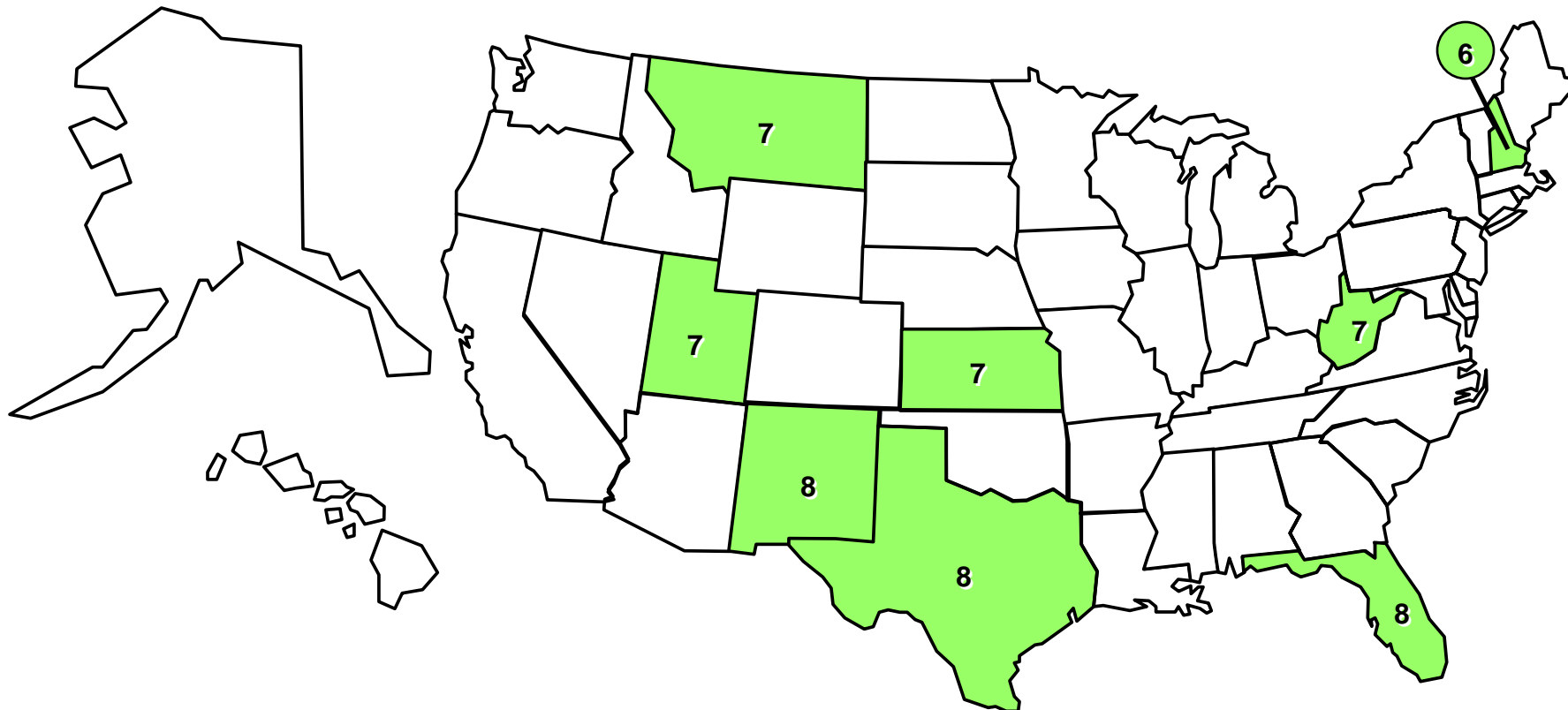
- Board of Health mandated screening to include full ACMG panel
- Anticipated start - March 2006 (currently no CF or expanded MS/MS – only MCAD and basic amino acids)



Washington



- July 11 – Washington CF NBS Advisory Committee concluded that CF meets Washington screening criteria
- Will recommend CF screening to Board of Health in October

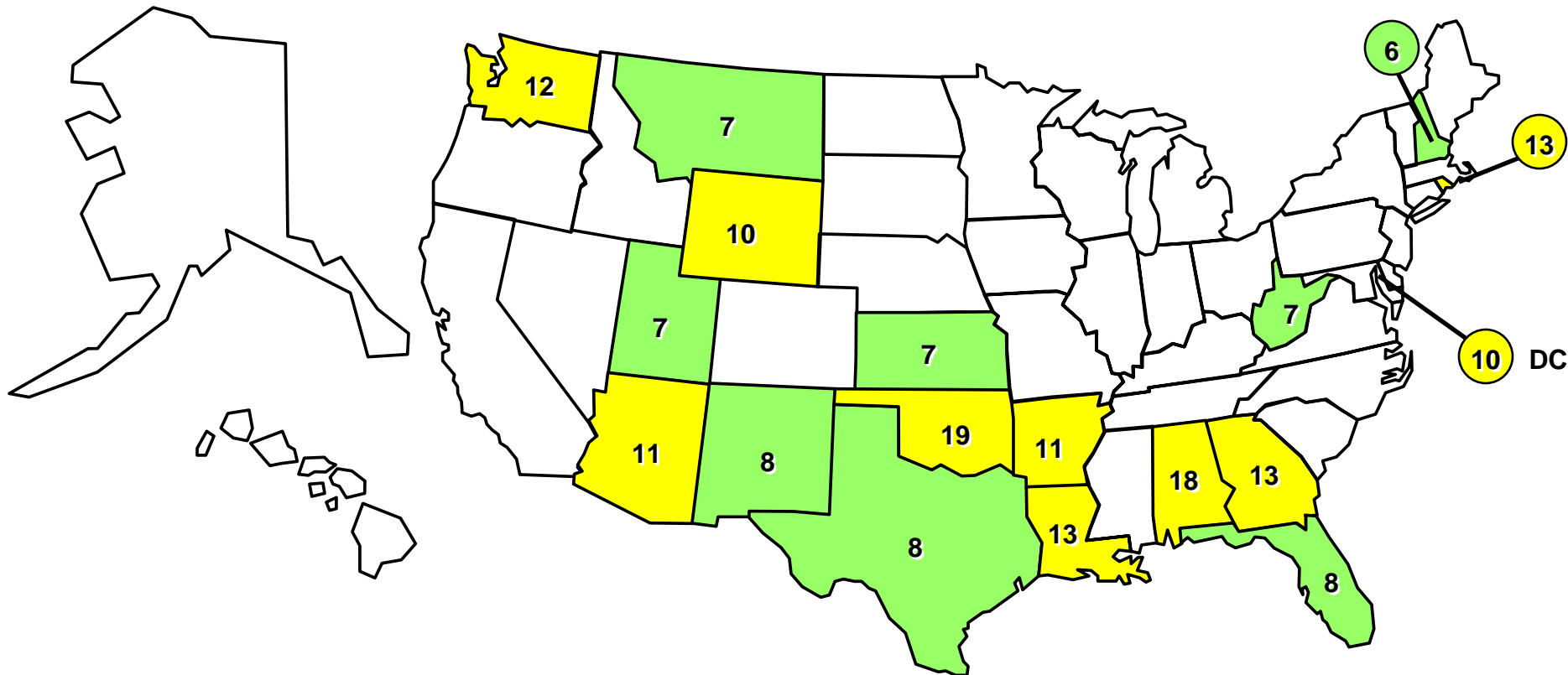


U.S. Newborn Screening

Conditions Required or Universally Offered – June 2005

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

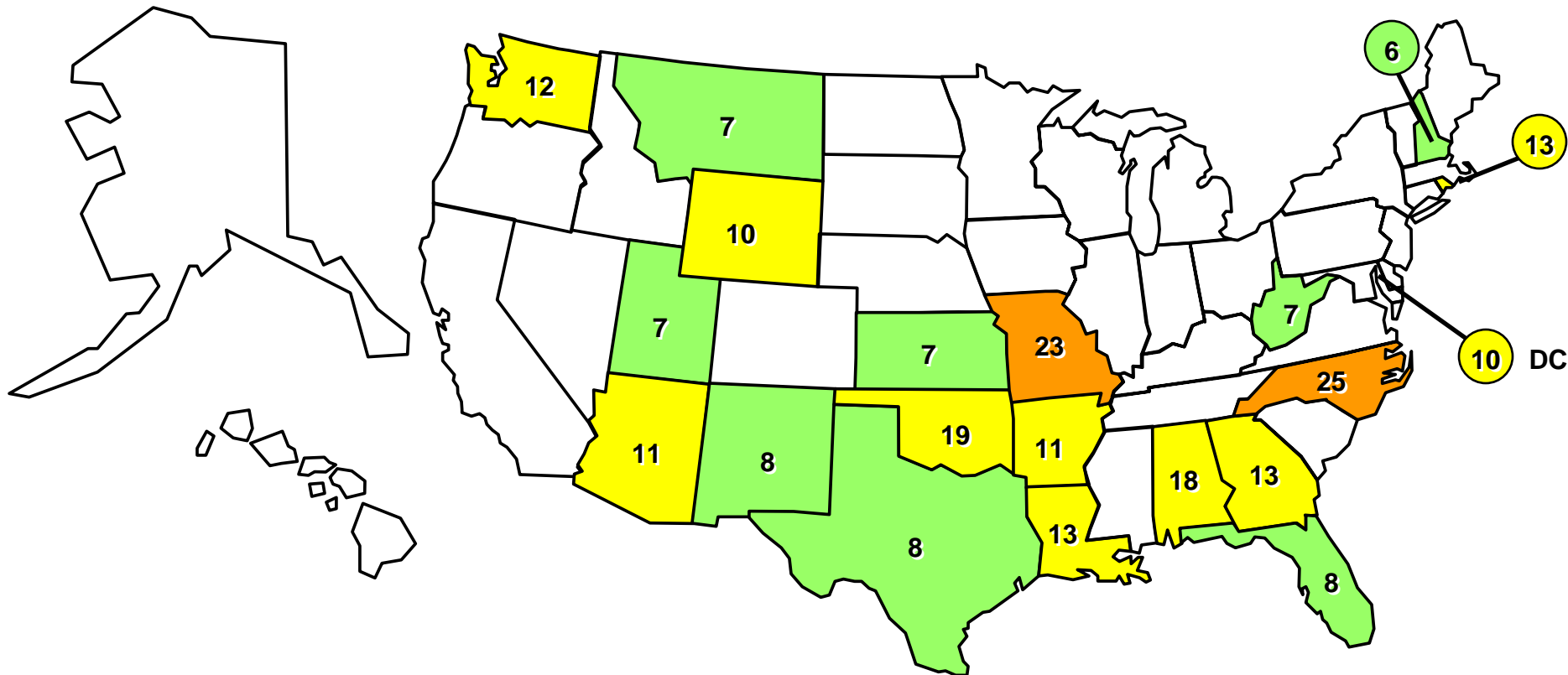
 <10 Disorders (8)



U.S. Newborn Screening

Conditions Required or Universally Offered – June 2005

- 10-19 Disorders (10) (Conditions available as an option to selected population are not counted)
- <10 Disorders (8)

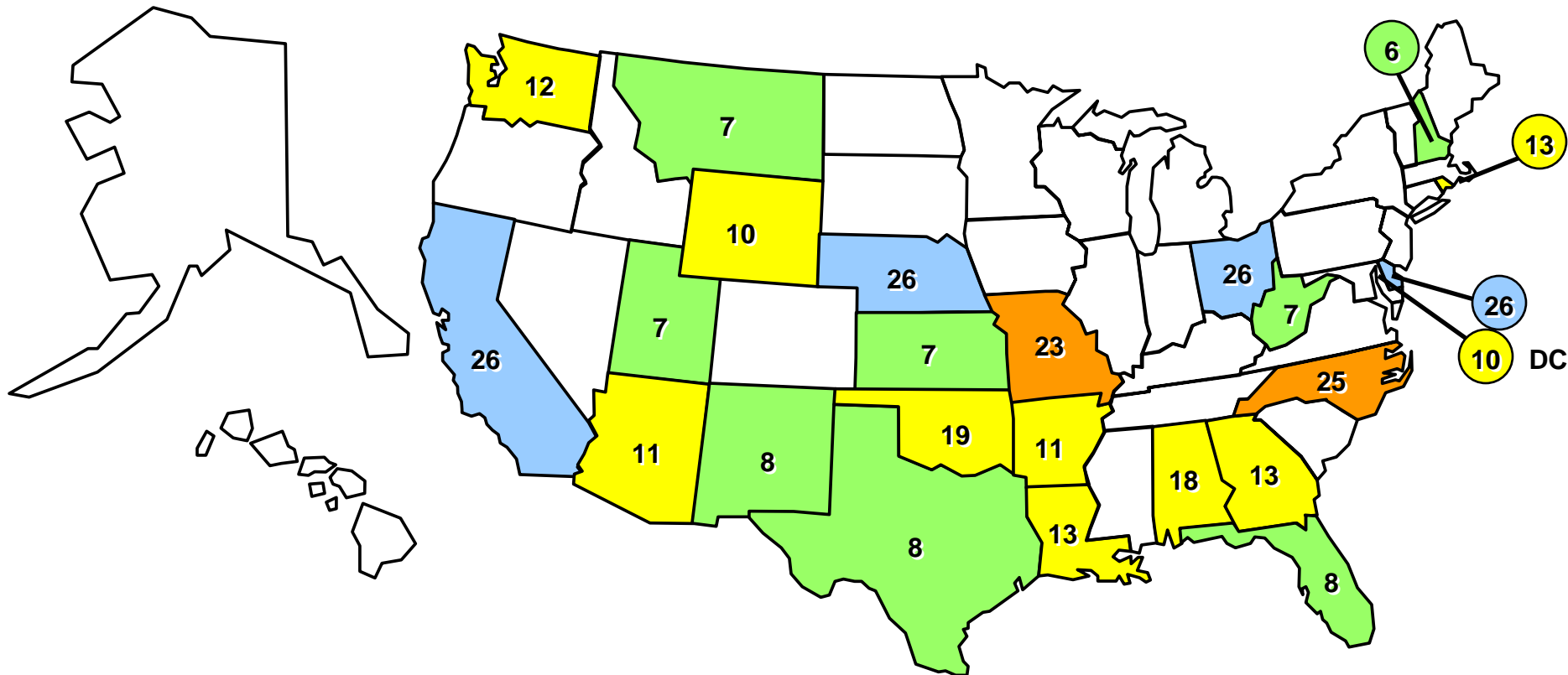


U.S. Newborn Screening

Conditions Required or Universally Offered – June 2005

- 23-25 Disorders (2)
- 10-19 Disorders (10)
- <10 Disorders (8)

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

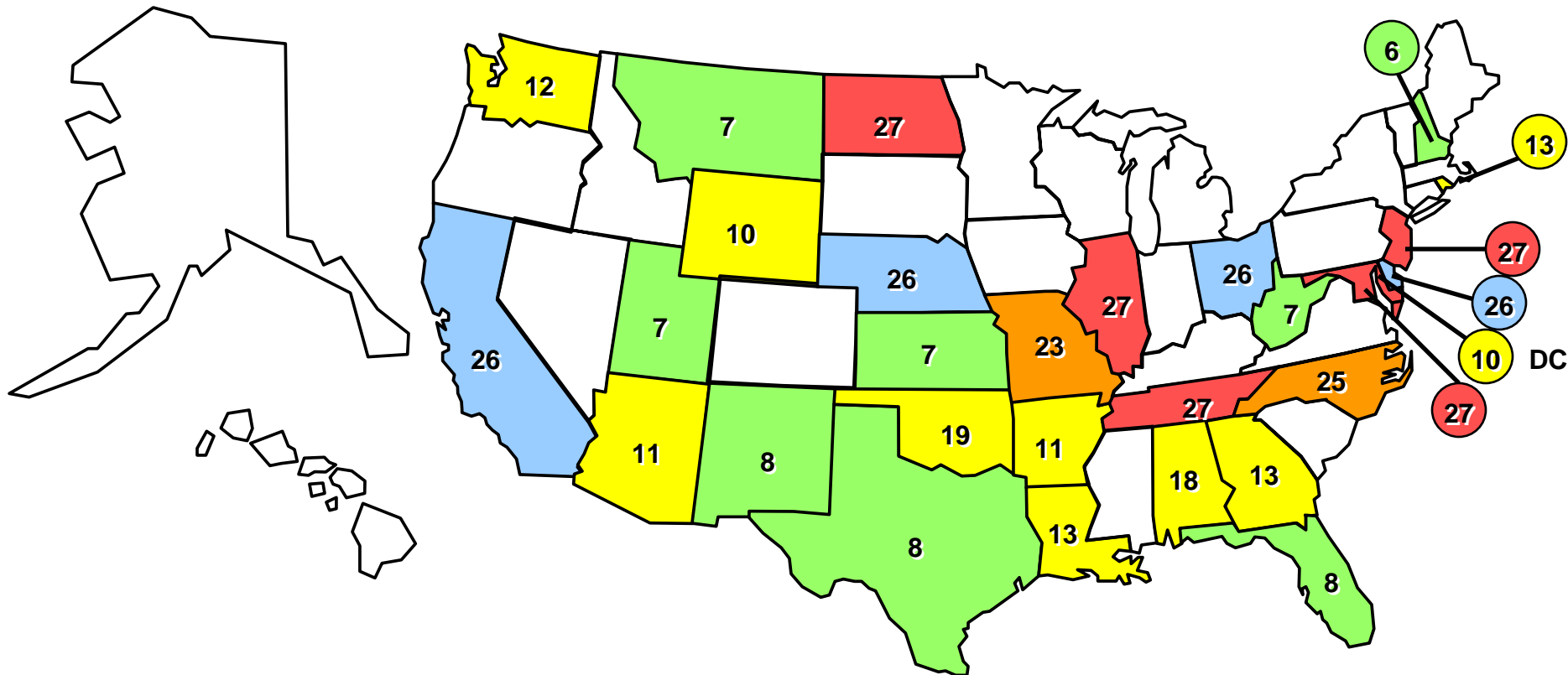


U.S. Newborn Screening

Conditions Required or Universally Offered – June 2005

- 26 Disorders (4)
- 23-25 Disorders (2)
- 10-19 Disorders (10)
- <10 Disorders (8)

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

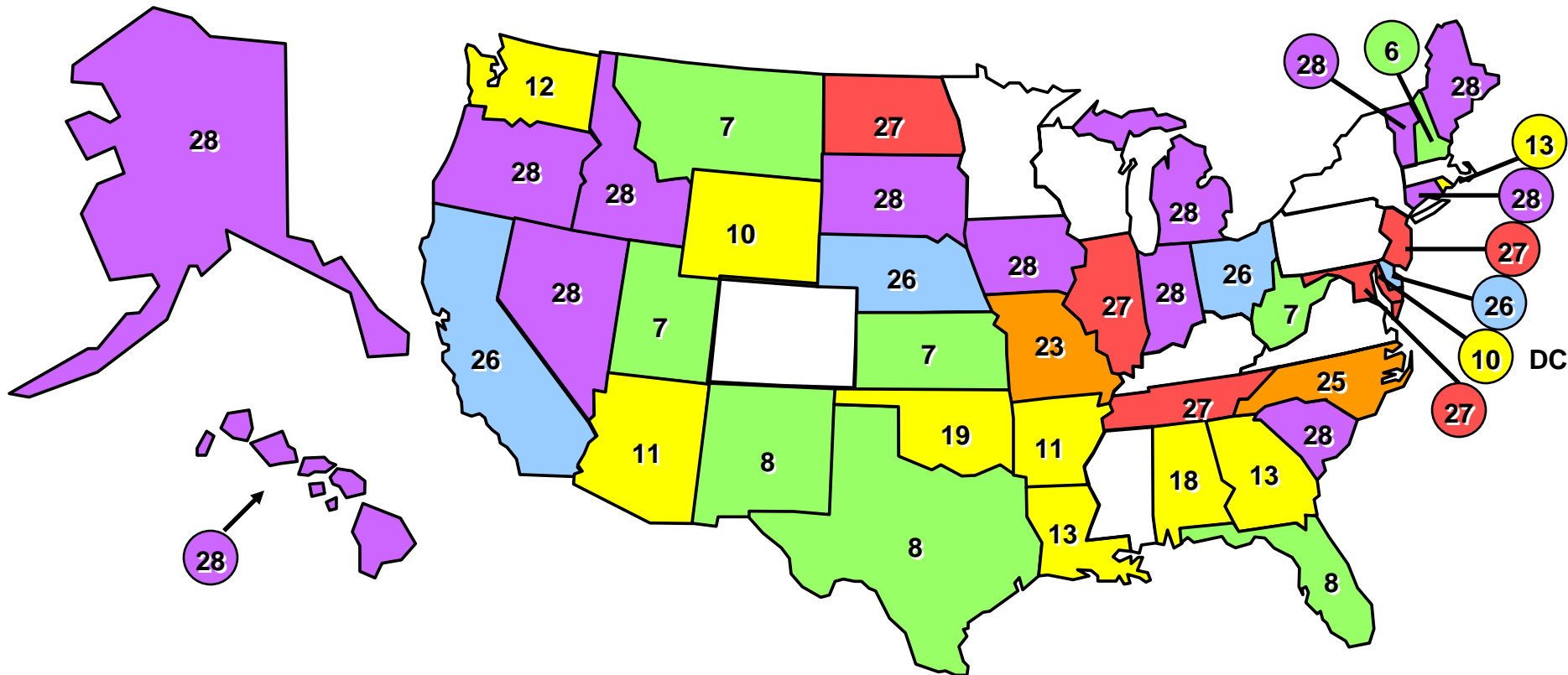


U.S. Newborn Screening

Conditions Required or Universally Offered – June 2005

- 27 Disorders (5)
- 26 Disorders (4)
- 23-25 Disorders (2)
- 10-19 Disorders (10)
- <10 Disorders (8)

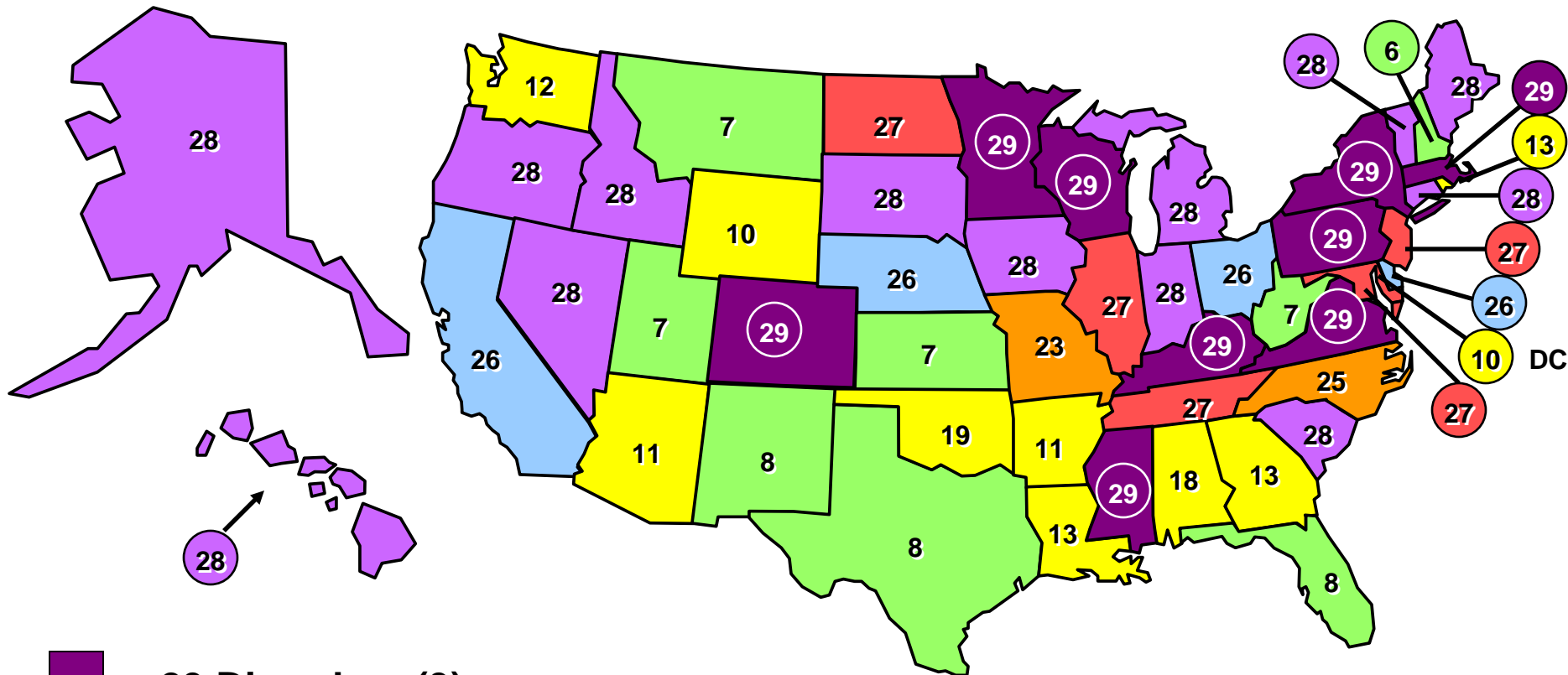
(Conditions available as an option to selected population are not counted)



U.S. Newborn Screening

Conditions Required or Universally Offered – June 2005

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



- 29 Disorders (9)
- 28 Disorders (13)
- 27 Disorders (5)
- 26 Disorders (4)
- 23-25 Disorders (2)
- 10-19 Disorders (10)
- <10 Disorders (8)

U.S. Newborn Screening

Conditions Required or Universally Offered – June 2005

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