

# Newborn Screening Activities Update

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## Alabama



- 2004 – Biotinidase Deficiency
  - 6 MS/MS Disorders



## California



- 2005 – Fee increase (\$60 → \$78) Jan. 1
  - 32 MS/MS disorders (tot. 87) Summer
  - CF & Biotinidase Deficiency Later



## Colorado



- 2004 – MS/MS at University of Colorado Medical School
- 2005 – Legislature to consider in July for 2006 implementation



## Connecticut



- 2004 – Increase from 5 → 30+ Feb. 1 (May 1: added 3; fee increase to \$28; dropped 2<sup>nd</sup> sample mandate – Oct 1: added 7 more – Nov 1: added 7 more)
- 2005 – Jan 1: Added 13 more
  - CF not included



## Florida



- 2005 – Increase from 5 → 30+ Feb. 1  
– CF & Biotinidase Deficiency Included



## Georgia



- 2005 – MCAD Deficiency Added Jan. 1



## Indiana



- 2004 – Fee increase to \$62.50 (includes \$32.50 laboratory surcharge)



## Iowa



- 2004 – Code Change: Birth Defects Institute to Center for Congenital and Inherited Disorder
- 2005 – Begin CF Pilot in Spring
  - Move to new facility with refrigerated storage for dried blood spots



## Louisiana



- 2004 – Started MS/MS Pilot (Nov. 1) 5 MS/MS Disorders (HCY, MSUD, MCADD, CIT, ASA)  
1 CIT on 1<sup>st</sup> day and 2 MCADD in 1<sup>st</sup> Month
- 2005 – Rule Change Eff. Jul. 1; Fee at least \$40



## Michigan



- 2004 – Added HCY, CIT, ASA (Oct. 1)
  - Fee increased to \$55.72 (Oct. 1)



## Minnesota



- 2004 – Pilot for Biotinidase Deficiency (Sept. 9)
- 2005 – Added Biotinidase Deficiency (Jan. 3)



## Missouri



- 2005 – Will “increase from 5 to ~25 early in 2005.”



## Nebraska



- 2004 – Lawsuit over right to dissent (currently not allowed) State won, now on appeal
  - Lawsuit over religious discrimination by allowing NICU to submit at 7 days – Injunction prohibiting collection until after day 7



## New Hampshire



- 2005 – In process of adding 4 conditions for a total of 10 – Adding CAH, BIO, MCADD, SCD – Continuing TOXO, PKU, CH, MSUD, HCY, GAL



## New York



- 2004 – Increase from 11 “to 31 by the end of 2004.”
- 2005 – “... additional expansion ... by Spring ... to 44.”
- 2005 – “This year ... one of the new tests will be for Krabbe Disease.”

Quotes from Gov. Pataki





## North Carolina



- 2004 – Biotinidase Deficiency (Nov. 2004)
  - Exploring possibility of adding CF



## Ohio



- 2005 – Anticipating addition of CF
  - Beginning CF validation process



## Oklahoma



- 2005 – Currently working on addition of CAH, CF, and MCADD
  - Fee increase expected but not yet final



## Oregon



- 2004 – Task Force convened to study and make recommendations on CF testing
  - New lab building purchased (relocation scheduled for 2006 – combines public health and environmental quality)



## Pennsylvania



- 2004 – Added contract laboratory
  - Major staff retirements/replacements
  - Recent Stakeholders meeting to begin to reshape program



## Rhode Island



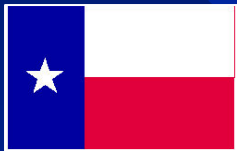
- 2004 – Advisory Committee - voted to recommend, to Genetics Advisory Committee and Director of Health, expansion to recommended core group.
- 2005 – Action to change Regulations currently underway for expansion.



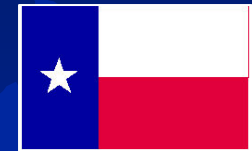
## South Carolina



- 2004 – Expanded to 30+ Conditions (Nov. 1)  
(previously mandated but not screening)
  - Fee increased to \$42 (Nov. 1)



## Texas



- 2004 – TMA/MOD/TDH (DSHS) Organized Stakeholders Meeting (Dec.)
- 2005 – NNSGRC Review (Feb./March)
  - MOD Working with Legislature (expand to all core except CF & Biotinidase Deficiency)



## Virginia



- 2004 – Joint Commission on Health Care voted to expand from 9 to 30+
- 2005 – Will go to Legislature for Approval
  - Fee increase expected (\$32 -> ~\$50)



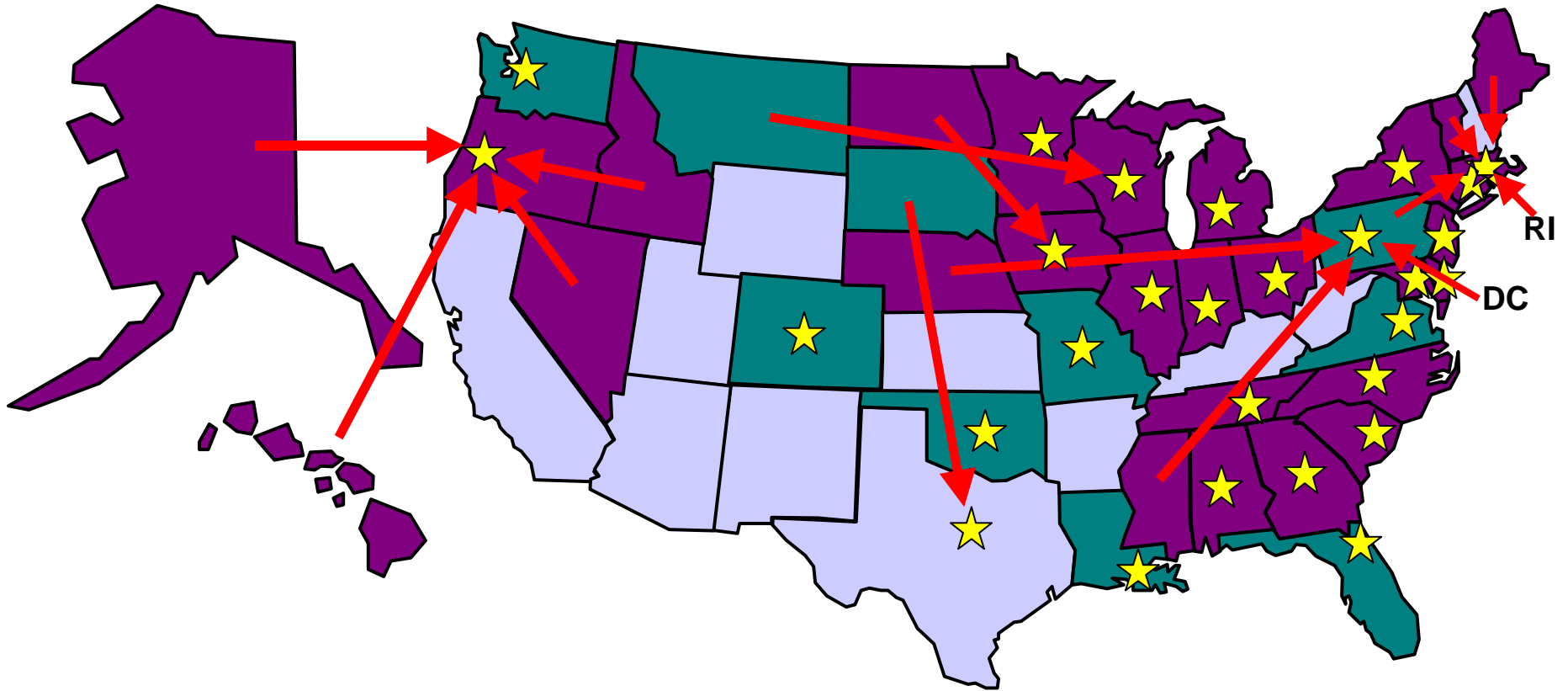
## Washington



- 2004 – Increased by 5 disorders (fee not currently supporting full panel of tests)
  - Began process to consider CF and to look at all others in core group.
- 2005 – Legislature will consider fee increase and whether to change voluntary hearing screening program.

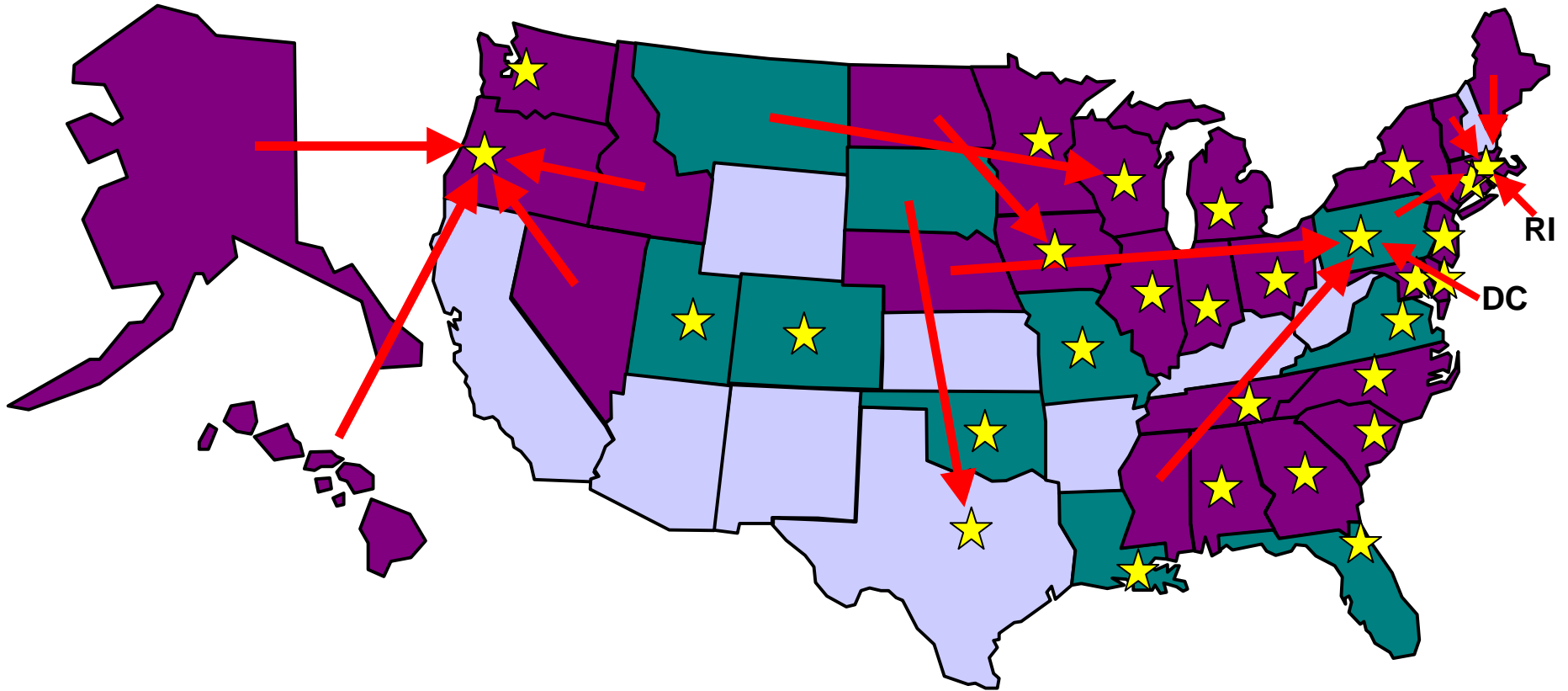
# Screening Changes

- Alabama → + BIO + 6 MS/MS Conditions
- Connecticut → + MS/MS beyond 3
- Florida → + CF + BIO + MS/MS Conditions
- Georgia → Began MCAD (previously mandated)
- Louisiana → Began pilot for 5 MS/MS Conditions
- Michigan → + 3 MS/MS
- Minnesota → + BIO
- New York → + MS/MS beyond MCAD
- North Carolina → + BIO
- South Carolina → + CF + BIO + 20 MS/MS beyond amino acids



- States With Mandated MS/MS Testing In Place
- States With MS/MS Pilots or Optional MS/MS Testing
- Pointer to Location of MS/MS Testing Laboratory
- Location of MS/MS Testing Laboratory

## States With MS/MS Screening September 2004

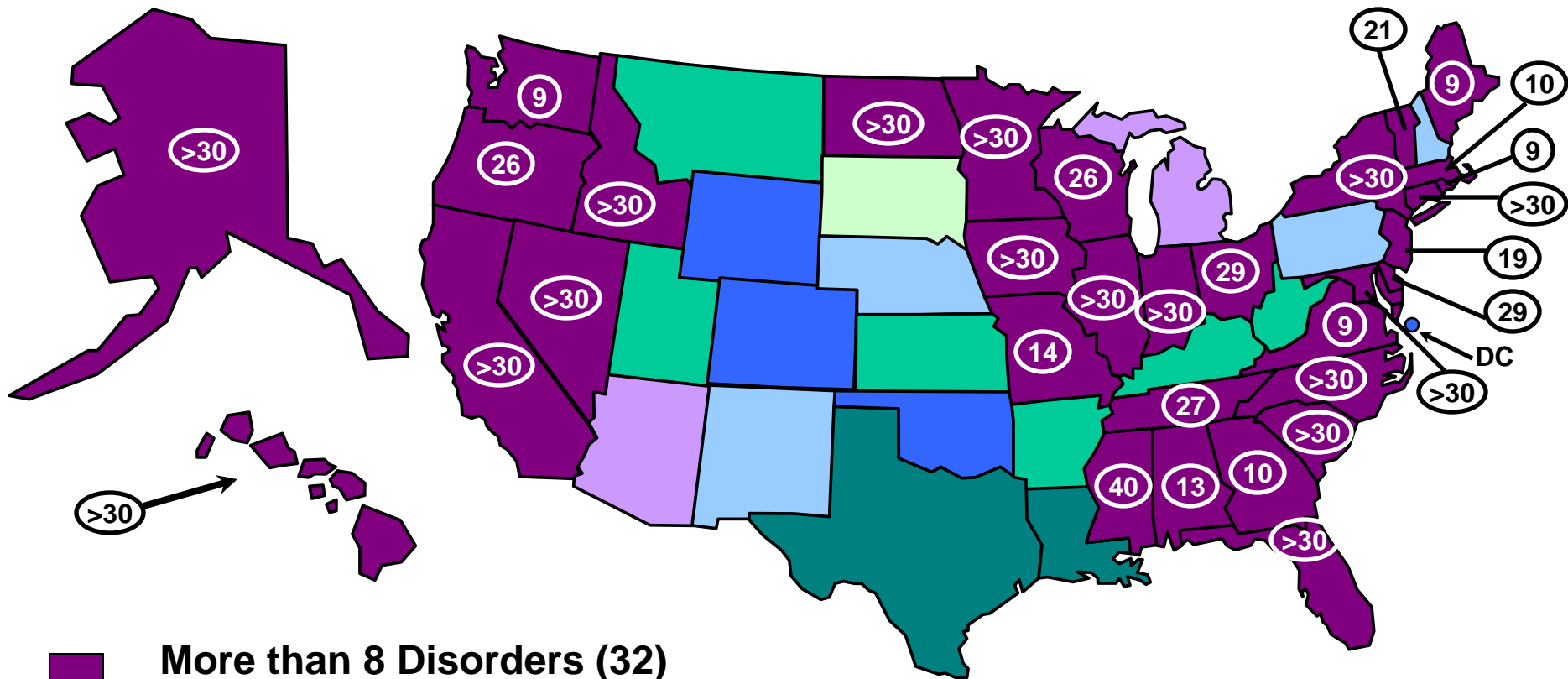


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- States With MS/MS Pilots or Optional MS/MS Testing
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## States With MS/MS Screening January 2005







More than 8 Disorders (32)

[More than 30 Disorders (14)]

8 Disorders (2)

7 Disorders (4)

6 Disorders (4)

5 Disorders (2)

4 Disorders (6)

3 Disorders (1)

## U.S. Newborn Screening

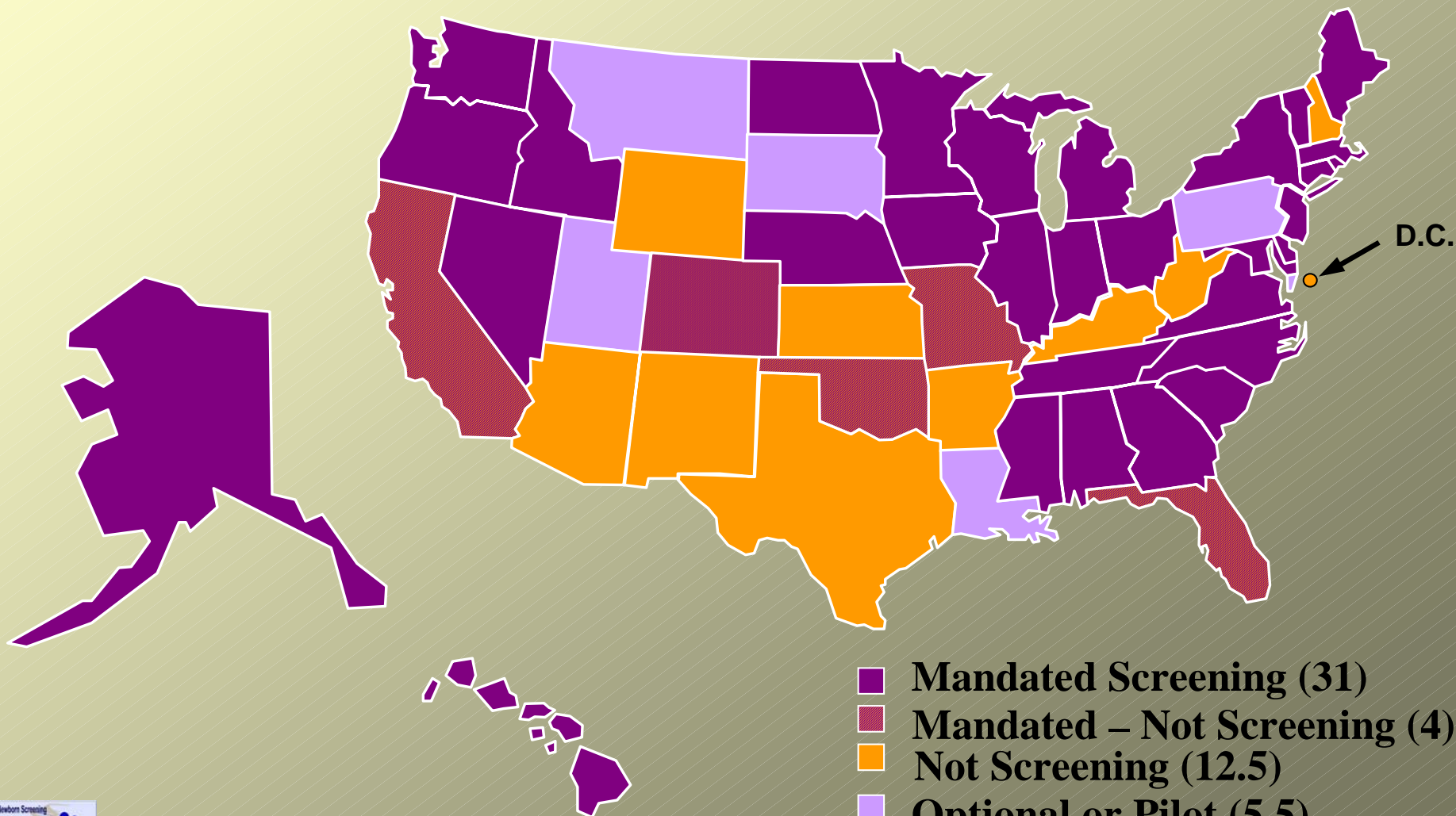
### Mandated Disorders – Jan 2005

(Note: Other disorders may be offered but are not mandated)

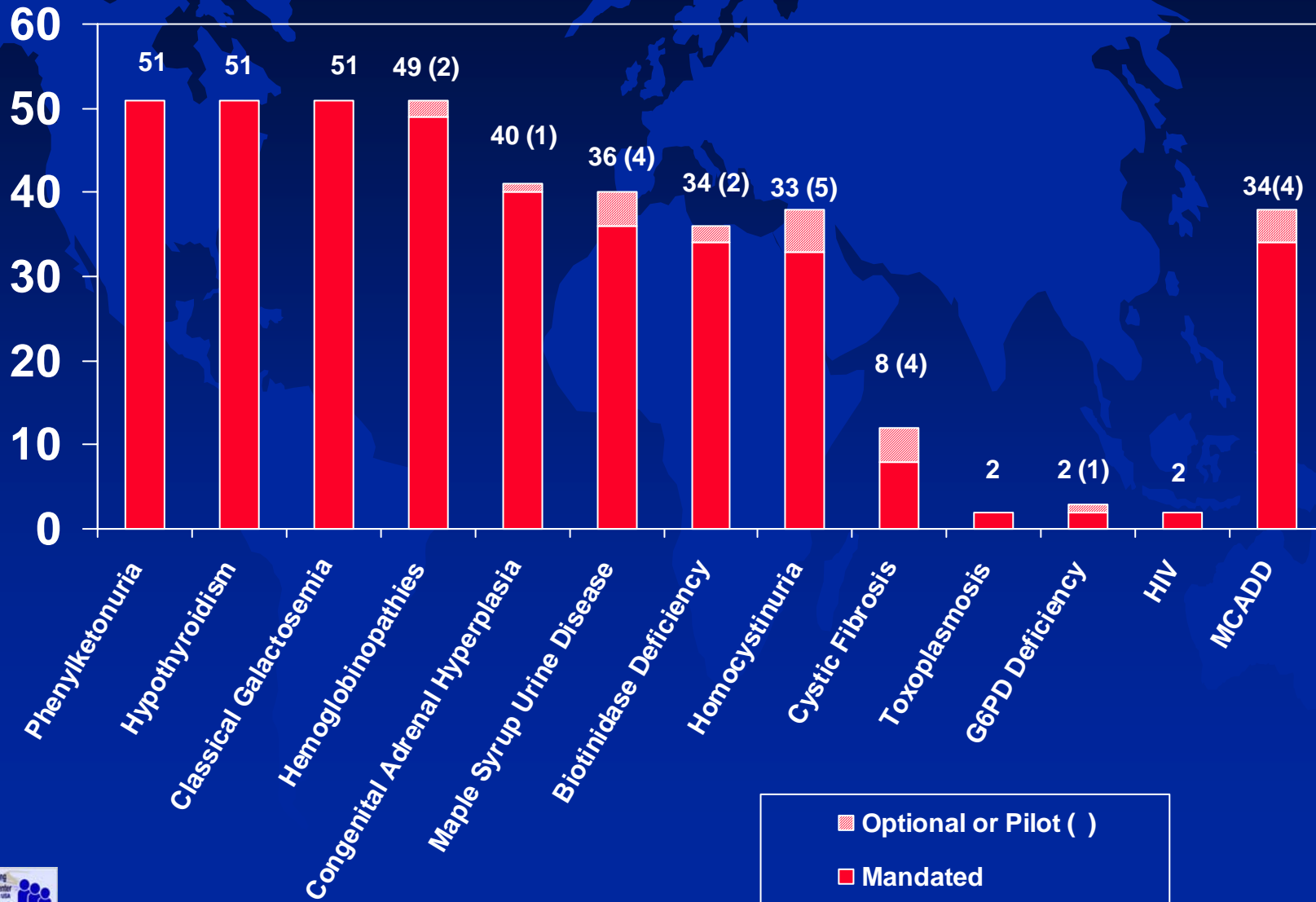


# U.S. Newborn Screening – 2005

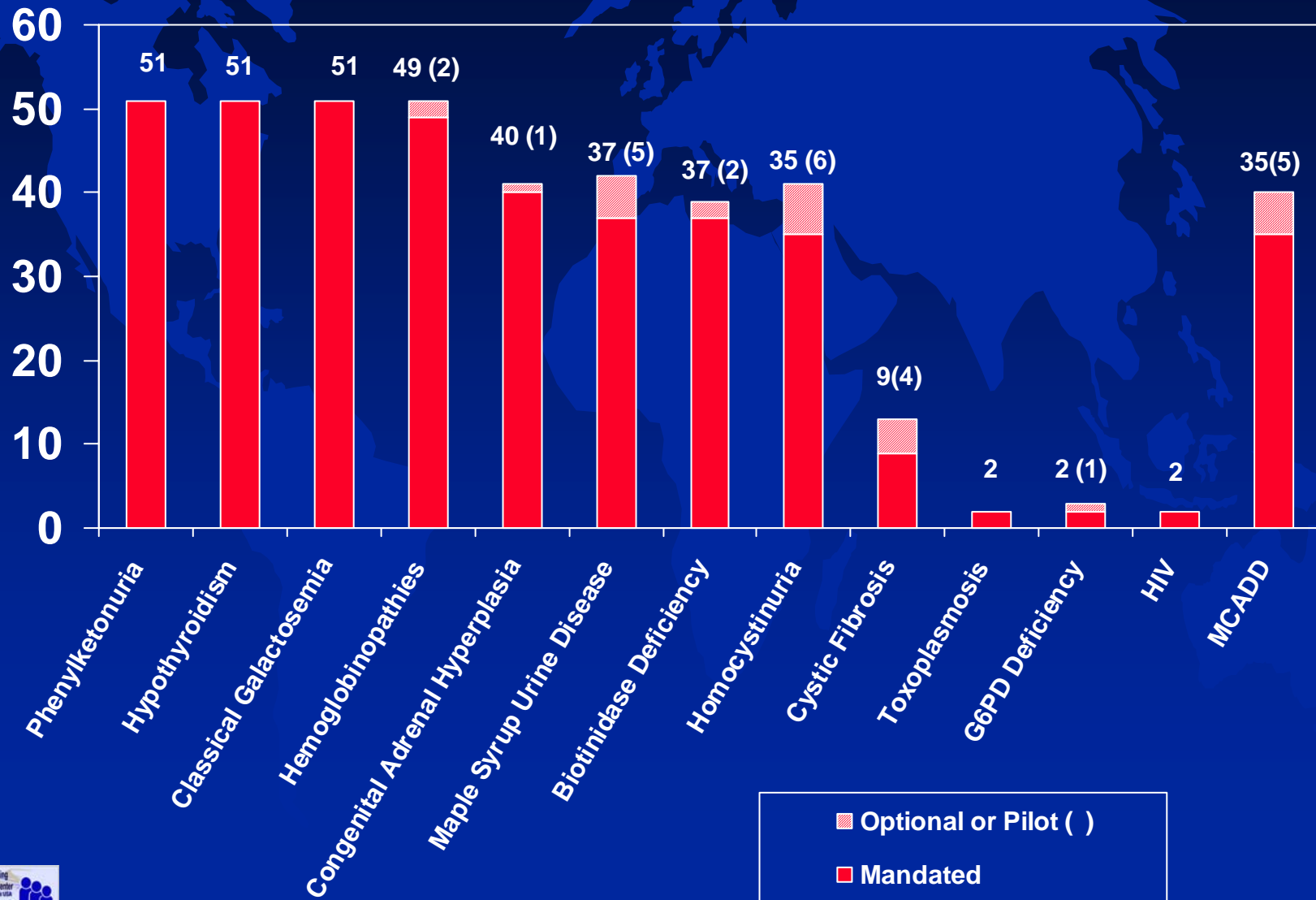
## Medium Chain Acyl-CoA Dehydrogenase Deficiency



# Disorders Screened in United States September 2004



# Disorders Screened in United States January 2005



Thank You

The image features the words "Thank You" in a large, white, 3D block font. The text is positioned centrally and appears to be floating above a dark blue silhouette of a world map. The background is a solid, deep blue color. The lighting on the 3D text creates a sense of depth and dimensionality.