

Status of Screening for Critical Congenital Heart Disease (CCHD) in the US

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The development of this presentation was supported by Cooperative Agreement #U22MC24078 from the Health Resources and Services Administration (HRSA). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of HRSA.



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The background of the slide features a close-up photograph of a newborn baby's hands, with the baby's face blurred in the background.



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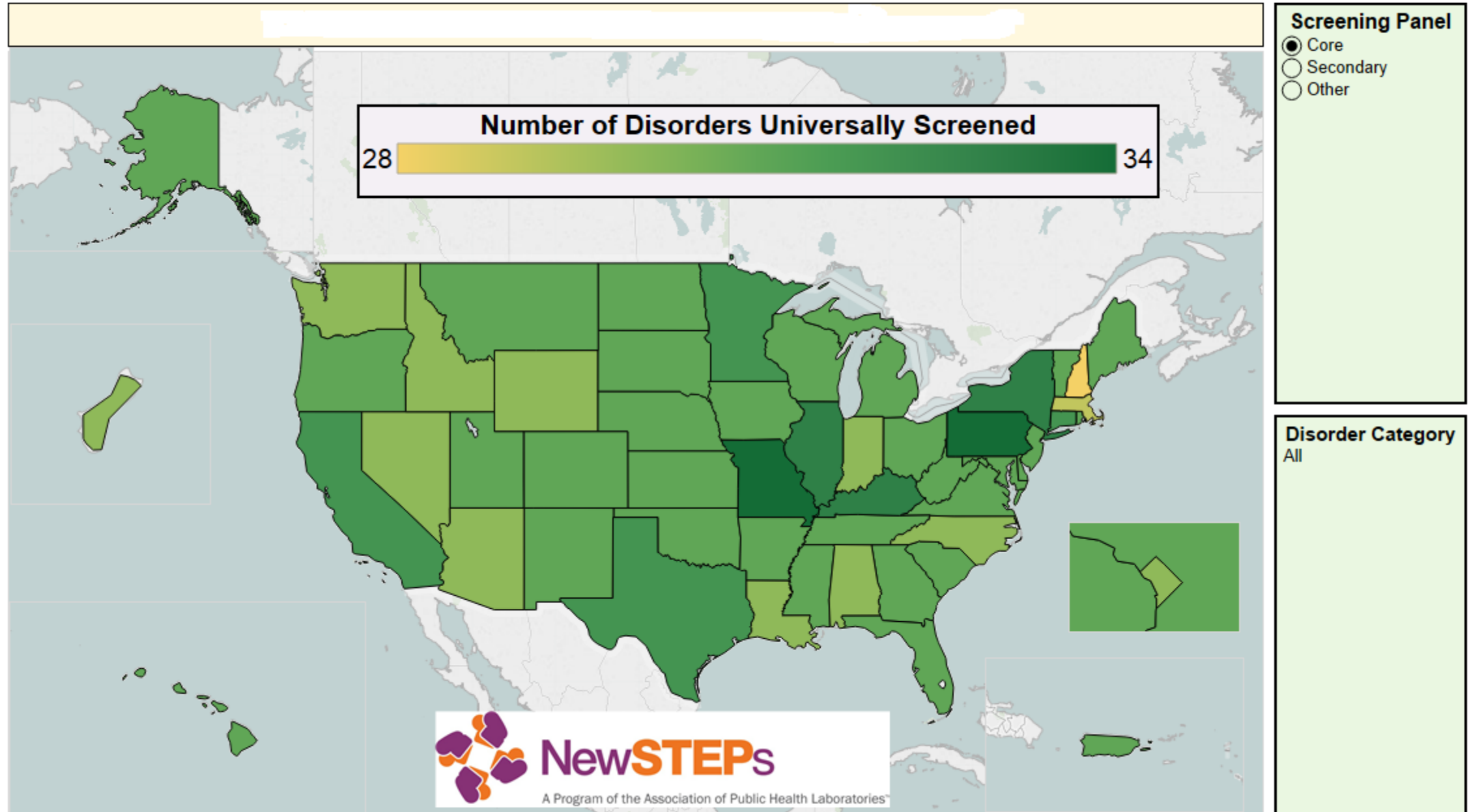
Recommended Uniform Screening Panel



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Universal Screening Status of the 34 Core Disorders (April 2017)



Status of Screening for Critical Congenital Heart Disease



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Adding CCHD to the RUSP



THE SECRETARY

September 2011

September 21, 2011

R. Rodney Howell, M.D.
Committee Chairperson
Secretary's Advisory Committee on Heritable
Disorders in Newborns and Children
5600 Fishers Lane, Room 18A19
Rockville, MD 20857

Dear Dr. Howell:

As indicated in my letter to you on April 20, 2011, I determined that the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) recommendation regarding implementation of universal screening for congenital heart disease (CCHD) to the Recommended Uniform Screening Panel (RUSP) is the most appropriate course of action. Consequently, I refer to the Secretary's Advisory Committee on Screening (SAC) regarding implementation of the SACHDNC and proposed screening technologies, development of public health programs, and strengthening of public health infrastructure. I have received and reviewed the requested ICC Plan of Action.

I have decided to adopt SACHDNC's first recommendation to add CCHD to the RUSP

As you know, congenital heart disease causes up to 3% of all infant deaths in the first year of life. Heart defects affect about 7 to 9 of every 1000 live births, one half of which could be detected and potentially treated by measuring blood oxygen saturation. Given this reality and the available information on the effectiveness of screening, I have decided to adopt the SACHDNC's first recommendation to add CCHD to the RUSP. In addition, I am requesting that the SACHDNC collaborate with the Health Resources and Services Administration (HRSA) to complete a thorough evaluation of the potential public health impact of universal screening for CCHD, as required by the authorizing statute, section 1111 of the Public Health Service Act (42 U.S.C. § 300b-10(b)(4)).

In arriving at my decision, I considered the recommendations from the ICC Plan of Action, the External Evidence Review, and the CCHD Workgroup Report. In addition to providing keen insight into the importance of early detection of CCHD, these reports have identified remaining evidence gaps about the public health impact of universal screening for CCHD. I have concluded that these evidence gaps should receive closer attention as implementation occurs. Specifically, it would be beneficial to states, health care facilities, and individual clinicians to have the SACHDNC and other public health experts, partner with HRSA to provide information about a number of issues, including but not limited to the following:

Other Recommendations Adopted:

The Committee therefore recommends the addition of Critical Congenital Cyanotic Heart Disease to the Committee's Recommended Uniform Screening Panel with the understanding that the following activities will also take place in a timely manner:

1. The National Institutes of Health shall fund research activities to determine the relationships among the screening technology, diagnostic processes, care provided, and the health outcomes of affected newborns with Critical Congenital Cyanotic Heart Disease as a result of prospective newborn screening;
2. The Centers for Disease Control and Prevention shall fund surveillance activities to monitor the Critical Congenital Cyanotic Heart Disease link to infant mortality and other health outcomes;
3. The Health Resources and Services Administration shall guide the development of screening standards and infrastructure needed for the implementation of a public health approach to point of service screening for Critical Congenital Cyanotic Heart Disease; and
4. The Health Resources and Services Administration shall fund the development of, in collaboration with public health and health care professional organizations and

1- Research regarding technology

2- Surveillance

3- Screening Standards

4- Education and Training

Page 3 – The Honorable Kathleen Sebelius

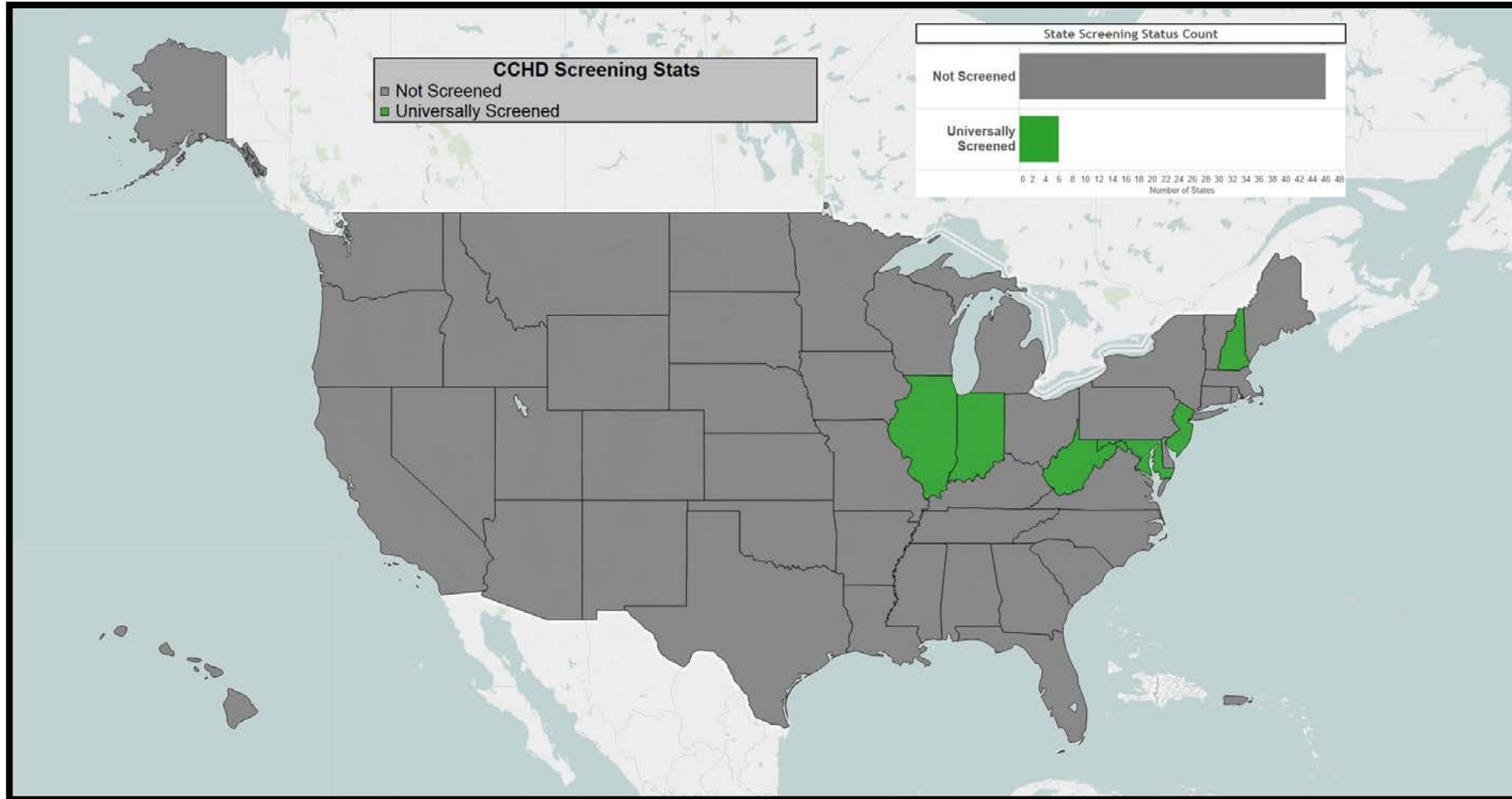
families, appropriate education and training materials for families and public health and health care professionals relevant to the screening and treatment of Critical Congenital Cyanotic Heart Disease.

The Committee fully recognizes that the various Agencies within HHS determine and carry out their missions within their goals and the budgets which they have available.

Sincerely yours,

R. Rodney Howell, M.D.
Chairperson

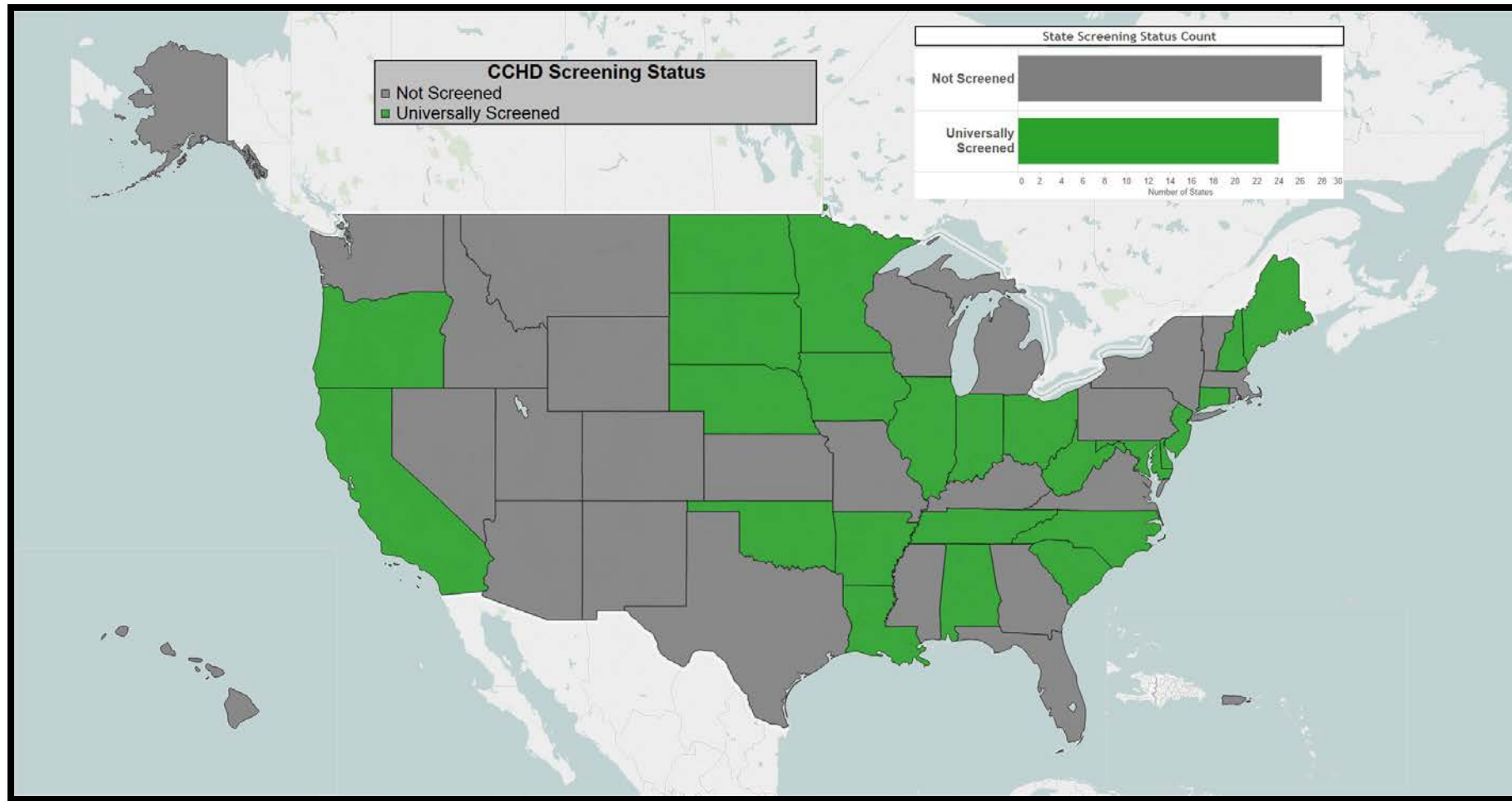
2012



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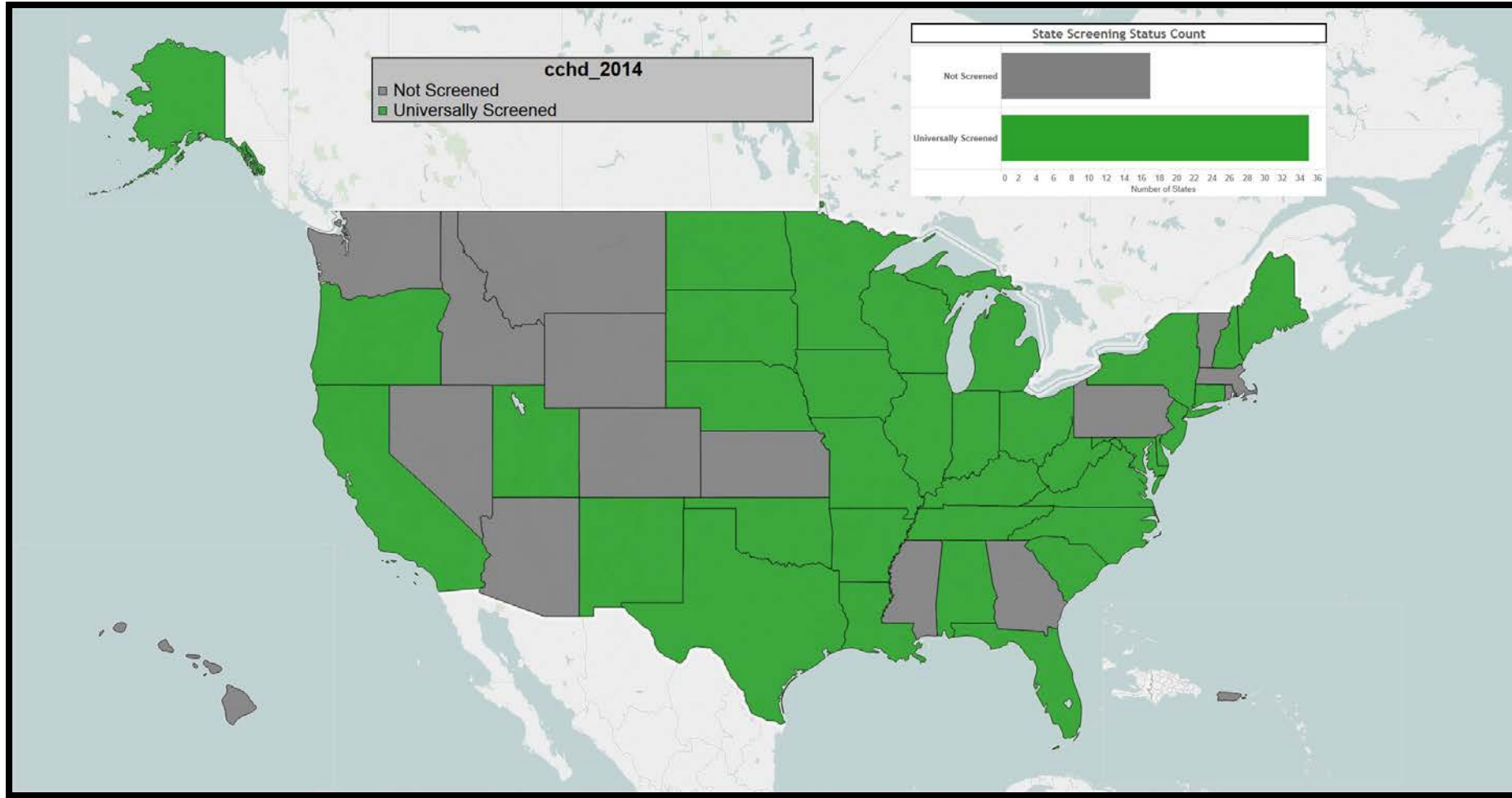
2013



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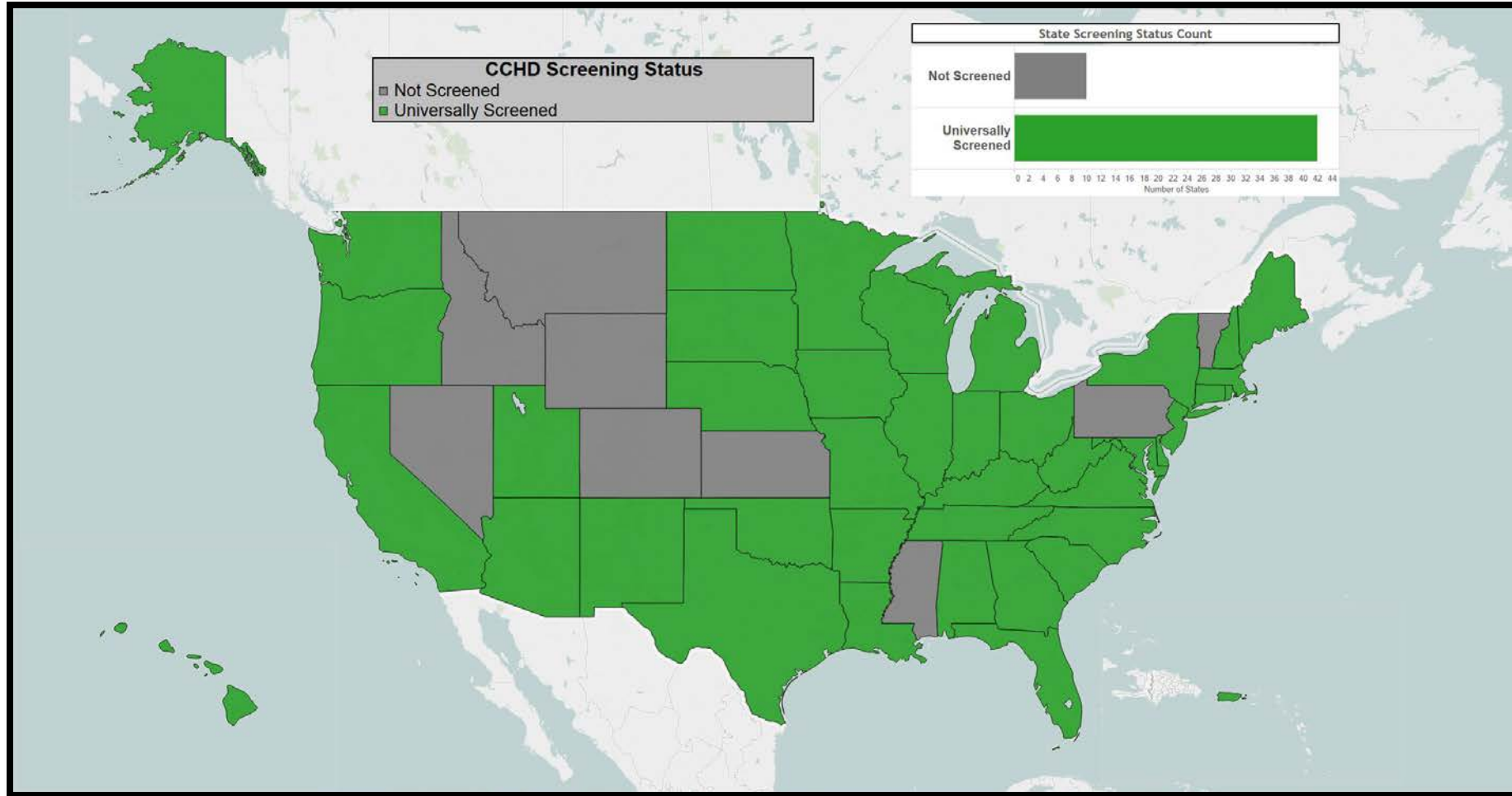
2014



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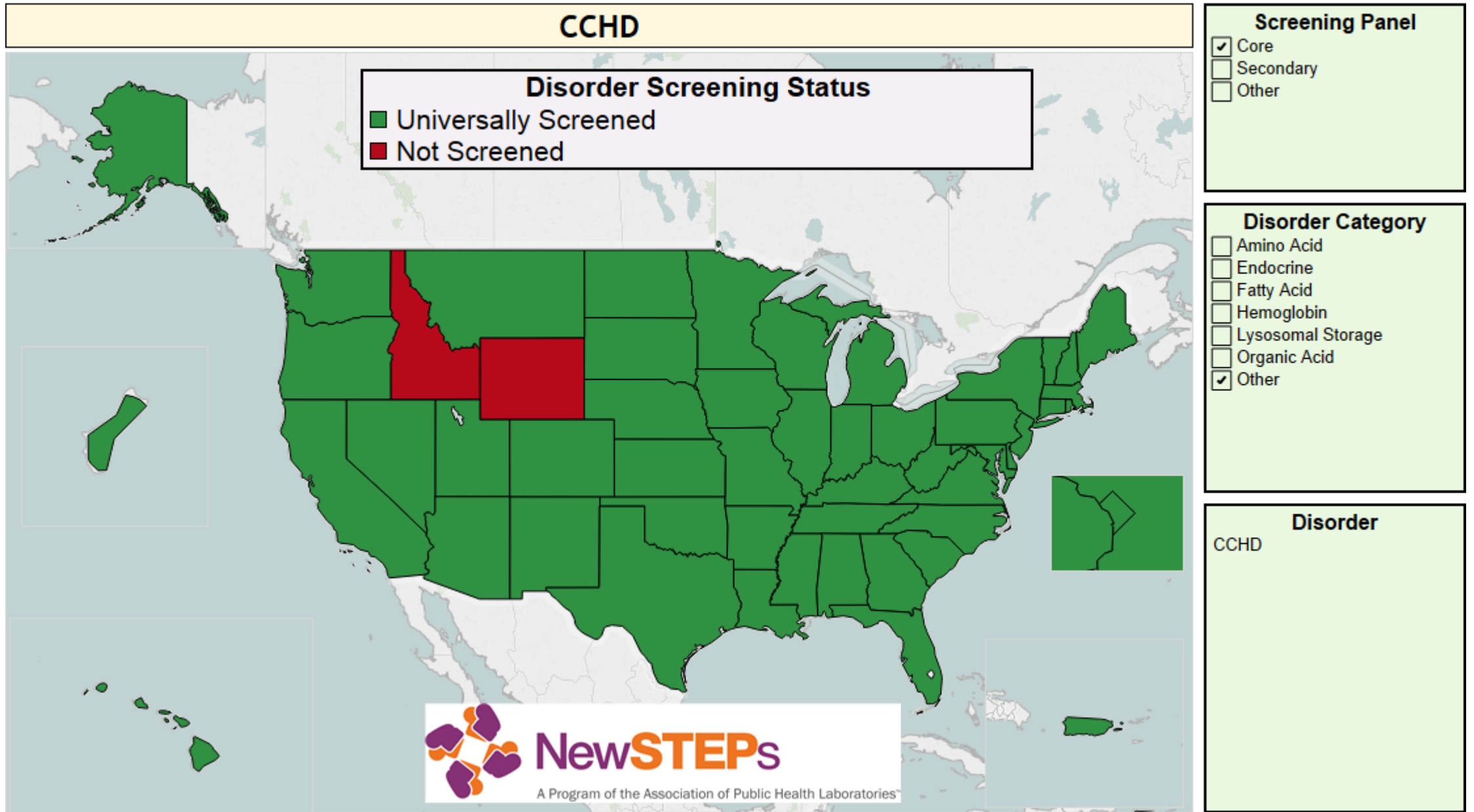
2015



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2017



Data Being Collected

- Status of NBS within each NBS program
- Universally Screened:
 - If public health is collecting data?
 - Yes/no
 - If yes, what data is being collected?
 - Aggregate from hospital (pass/fail/not done);
 - Individual data (pass/fail/not done);
 - Individual data (Final O₂ saturation data and time);
 - Individual data (All O₂ saturation data and times);
 - Other (please describe)



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Acknowledgements

Thank you NBS Programs

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