

Working to Expand Newborn Screening: the pulse oximetry story

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Executive Director



Who We Are

The Newborn Foundation and the Newborn Coalition work both domestically and internationally to leverage health IT and technology innovation to improve outcomes and reduce disparities for the newest, most vulnerable citizens.

We strongly believe that it is not enough just to implement screening, but that there is a responsibility to facilitate follow-up.

Technology and infrastructure can and should play a larger role in the early identification and prevention of newborn health issues.

What We Do

Newborn Foundation

- Policy Development
- Process Design
- Non-Governmental Organization

Newborn Coalition

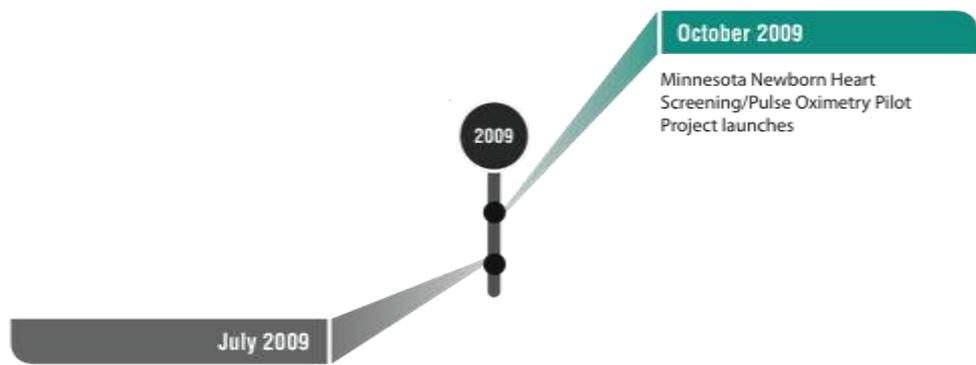
- Legislative Advocacy in the US and Internationally

Why We Care

The catalyst for our beginning was the birth of a baby named Eve in Minnesota who was diagnosed with a Critical Congenital Heart Defect (CCHD) at two days old.

- Congenital heart defects is the most prevalent of all birth defects, affecting 1in100(ish) births in the United States.
- Pulse oximetry is a simple, non-invasive, and cost effective screening tool that can identify CHD before the baby leaves the birth setting.





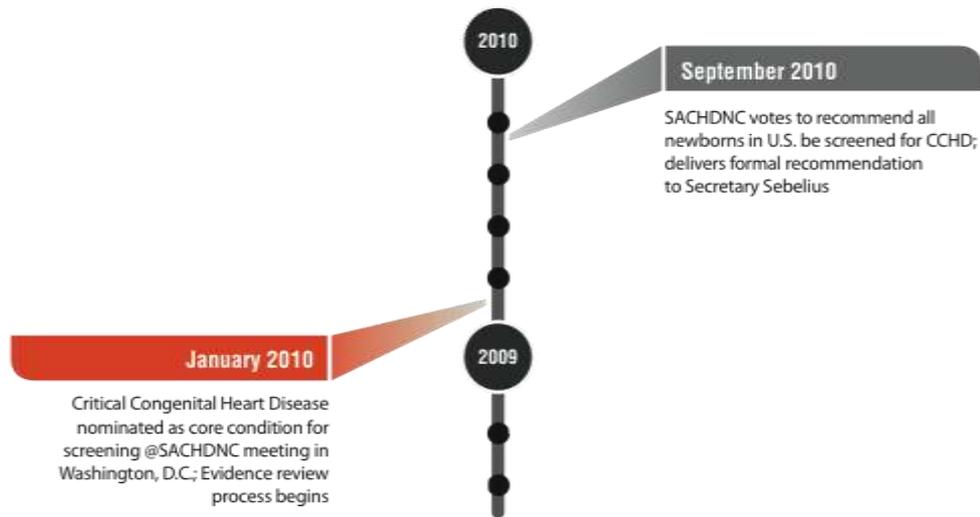
July 2009

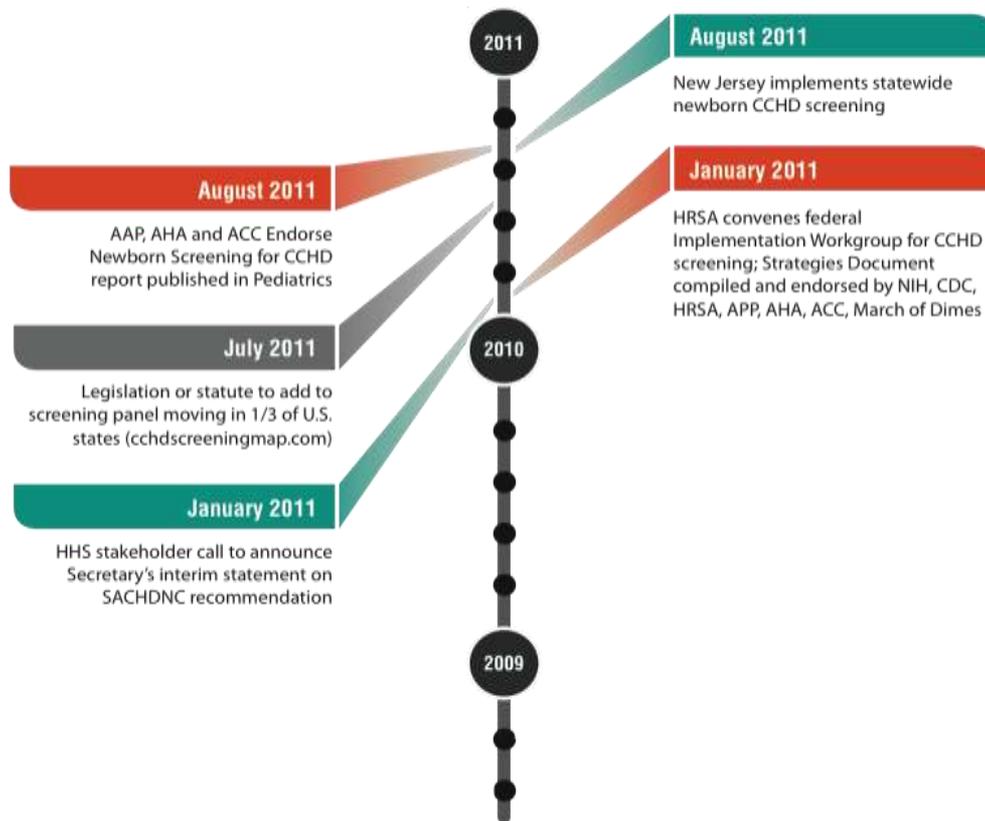
AAP/AHA statement on pulse oximetry screening; European studies published supporting routine screening to detect heart disease in newborns

October 2009

Minnesota Newborn Heart Screening/Pulse Oximetry Pilot Project launches





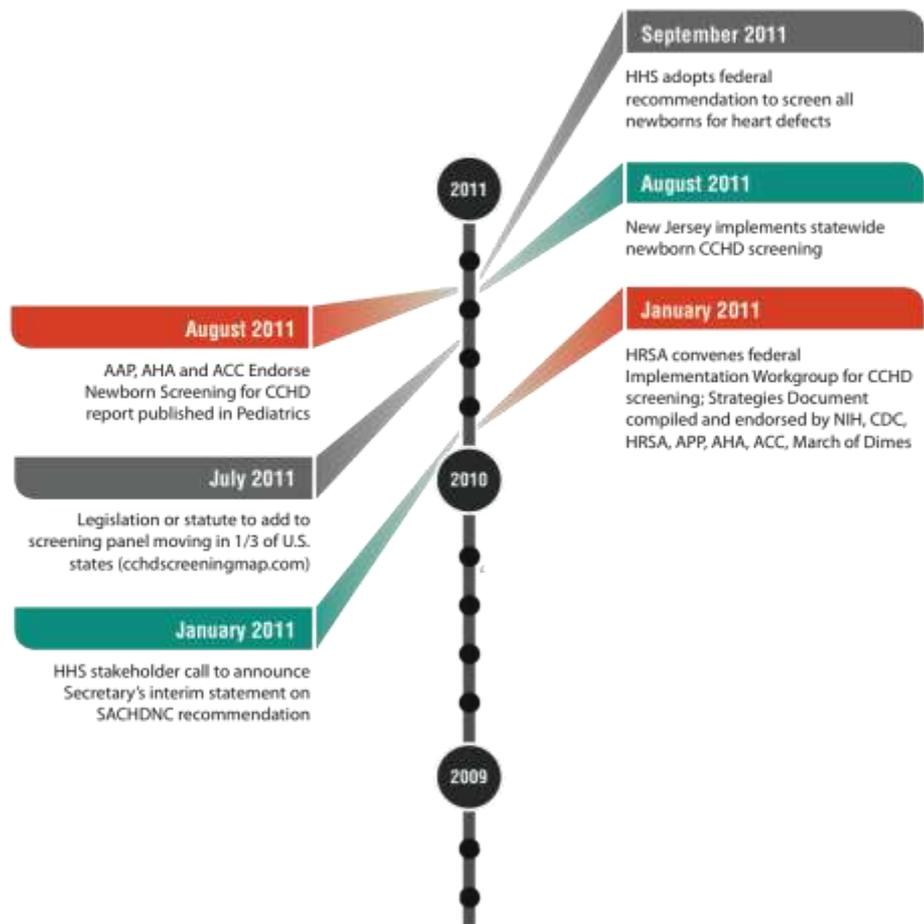




August 2011

New Jersey becomes the first state to mandate screening.

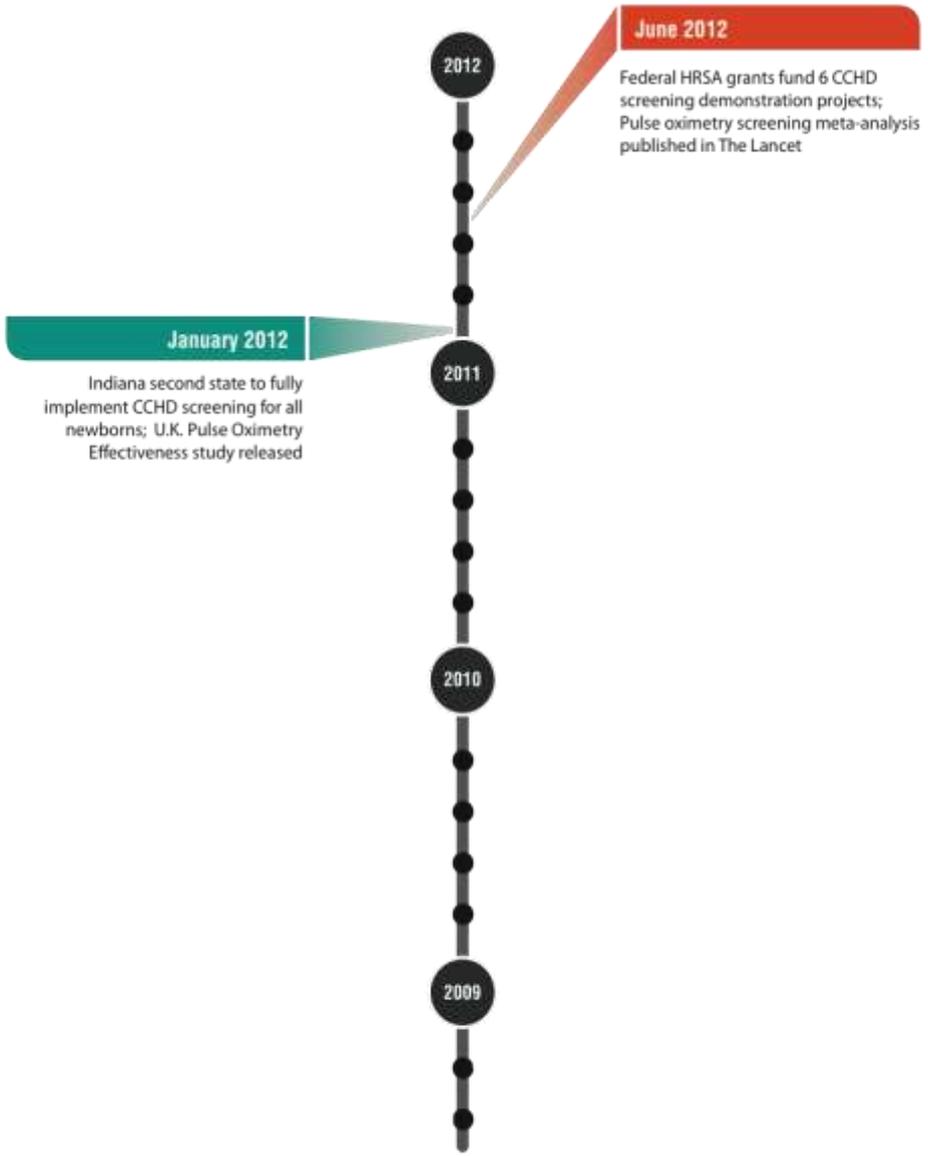
A baby was identified with a CCHD on the first day.



In September of 2011 Health and Human Services Secretary, Kathleen Sebelius, formally recommended that **all newborns** be screened for Critical Congenital Heart Defects using pulse oximetry.

- Cabinet-level officials are *generally* able to make non-binding recommendations however there is a special advisory group for newborn screening.
- Responsibility falls to the states for implementation.
 - Can be done through regulation or legislation.





Opposition to Legislation

- State Hospital Associations
 - Many pieces of legislation are unfunded mandates.
 - Concerned about cost of pulse ox probes
 - Workflow disruptions during implementation
 - Reporting requirements
- State Departments of Health
 - Did not believe that a point of care examination fell under their jurisdiction.

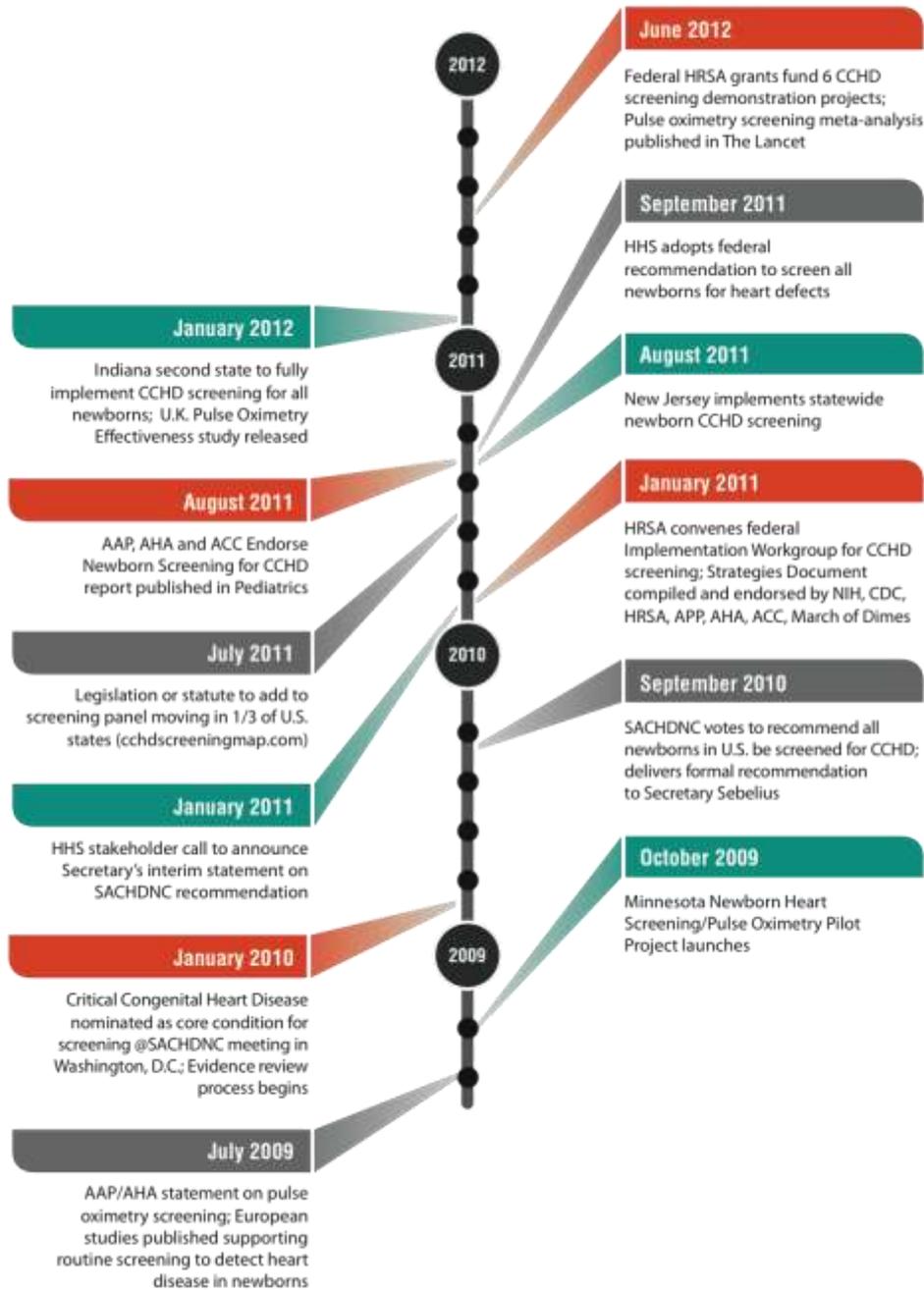
Common Questions | Comments

- Aren't hospitals already doing this?
- How long do we have to do this?
- The screening may be cheap but the defects we *do identify* will be expensive.
- This is a low priority for our state / We cannot afford this right now.
- Our state does not have adequate capacity for follow-up.

Our state does not have adequate capacity for follow-up.

- Yet.
- Difference between access to a solution and the existence of a solution.
- Not an excuse for allowing preventable morbidities and mortalities.

Create an environment in which the market can be most effectively reactive.



Thank You

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www.newborncoalition.org

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