

Newborn Screening Education in a Prenatal Setting

Educational Outreach Efforts by the Iowa
Newborn Screening Program Follow Up Staff

Lessons from Brody



When *Should* Parental NBS Education Occur?

- ▶ During a prenatal visit in a controlled environment.
- ▶ Close enough to delivery so that there is a high likelihood of it being remembered, but not so close that they deliver before the education is provided.

How Should NBS Education Occur?

- ▶ Should occur in the prenatal setting *first*
- ▶ Should be *reinforced* at the time of collection
- ▶ Whenever there is an *abnormal* result
- ▶ NBS results should be discussed at the *first well baby visit* and further need for education should be assessed at that time

Serendipity



Where the Education Takes Place



What Happens?

- ▶ Introduce ourselves
- ▶ Show the “Saving Babies One Foot at a Time” video
- ▶ Review key components from video
- ▶ Brief overview of what disorders are screened for in Iowa

What Happens? – Con't

- ▶ Hand out NBS brochure
- ▶ Show the dried blood spot card
- ▶ Show the ABR machine
- ▶ Talk about DBS retention/research
- ▶ Q&A Session

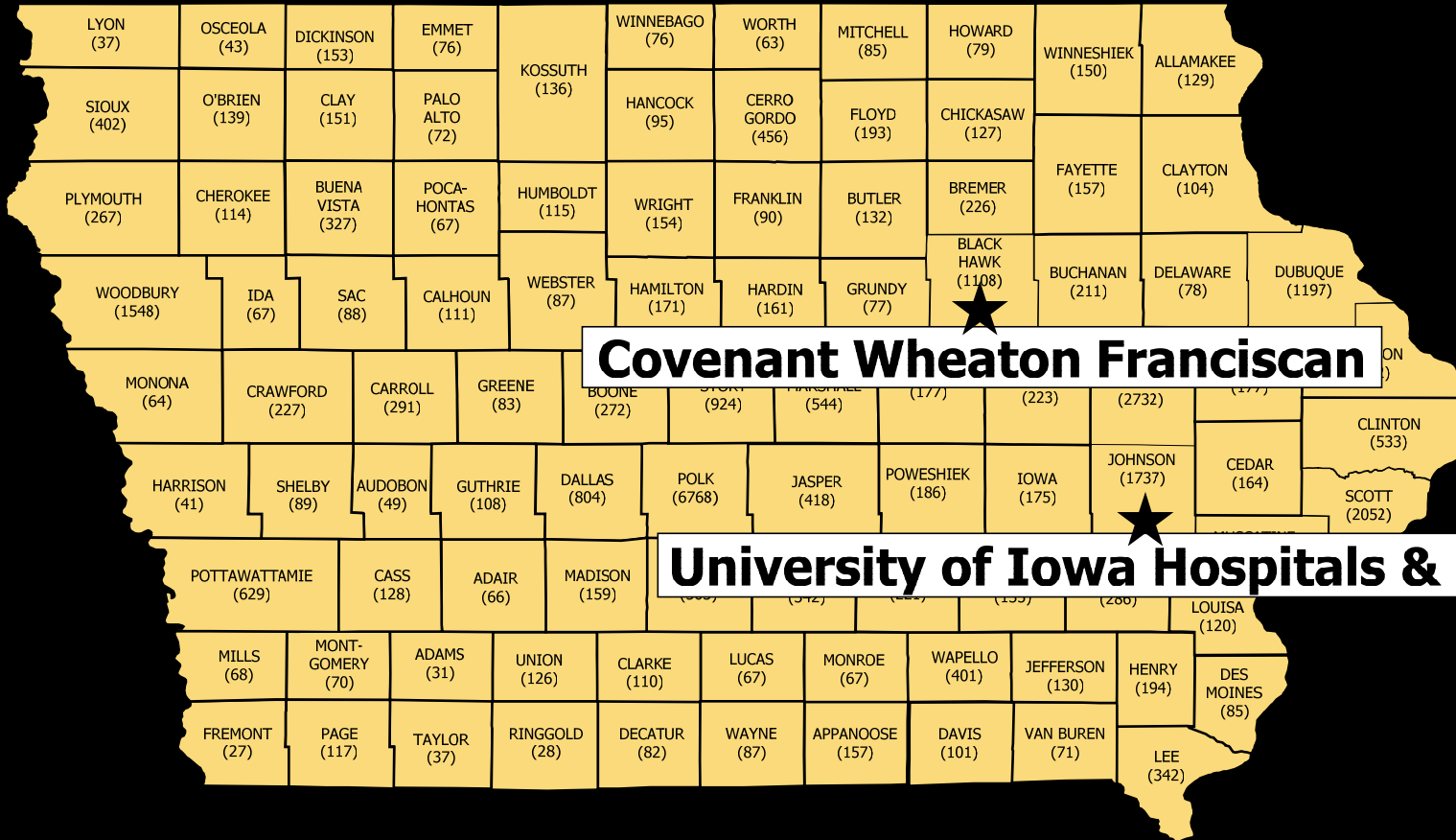
Common Questions

- ▶ How does Iowa compare to the rest of the country?
- ▶ Why don't other states test for everything?
- ▶ How is the sample processed in the lab?
- ▶ When was NBS made mandatory?
- ▶ How will we know when the NBS is collected?
- ▶ Who can we call to get the results of the NBS?

Feedback

- ▶ Parents are glad they know about NBS
- ▶ Parents plan to ask their baby's physician about NBS

Future Expansion



Future Goals

- ▶ Do more NBS educational outreach to all stakeholders
- ▶ Continue to foster collaboration
- ▶ Reach out to prenatal care providers and birthing centers across Iowa to begin collaboration on NBS education
- ▶ Every parent of a newborn has heard about NBS before their baby's NBS is collected

Graduates of NBS Prenatal Education



Centering Healthcare Information

- ▶ www.centeringhealthcare.org
- ▶ “Centering is a model of group health care, changing how people experience their care. Health assessments, education, and support are provided in a group facilitated by a care provider”

Acknowledgements

- ▶ Laura Dellos, ARNP and Kristi Borowski, MD
- ▶ Saving Babies Foundation
- ▶ LTFU Staff
- ▶ Medical Consultants
- ▶ Medical Director
- ▶ Iowa Department of Public Health
- ▶ Department of Pediatrics / U of Iowa Children's Hospital

NBS Lab



Short Term Follow Up

