Assessing Parental Attitudes About Newborn Screening for Late Onset Disorders

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HRSA MCHB H46MC24091-05-02
Hmmmm... What do parents think about newborn screening for late onset disorders?
Let’s ask parents!!

Great idea!!
How We Did It

- Design survey for Hawaii
- Test survey
- Get IRB approval
- Administer survey at Baby Expo to parents of children 4 or under and pregnant parents
- Give string backpack as incentive
How We Did It

- Revise survey for Washington & California
- Get IRB approval
- Administer survey at Kid’s Expo to parents of children 4 or under and pregnant parents
- Give string backpack (WA) or $5 Starbucks gift card (CA) as incentive
What did we ask?

- Knowledge of newborn screening
- Attitude towards newborn screening for late onset disorders
- Preferred methods for education and contact
Who Completed the Surveys?

- 523
- 134
- 221
Who Completed the Surveys?

676 moms
174 dads
18 moms and dads

Total Surveys Completed: 868
Who Completed the Surveys?

397 (45.7%) currently pregnant
Who Completed the Surveys?

Ages of Respondents

- 18-29: 39%
- 30-39: 52%
- 40+: 9%
Who Completed the Surveys?

- < high school: 1%
- High school or GED: 33%
- College graduate: 50%
- Postgraduate degree: 16%
Who Completed the Surveys?

Have a child with a special health need 7.8%  
(National rate is 12.8% from HRSA National Children’s Survey)
Do you know that your child has received or will receive NBS within a few days of life?
What do you think about the Department of Health providing NBS?
Do you want your newborn screened when there is a KNOWN prevention or treatment for the disorder?

If symptoms appear before 6 months

% that answered

Yes

No

Hawaii
N = 523

Washington
N = 134

California
N = 221
Do you want your newborn screened when there is a KNOWN prevention or treatment for the disorder?

If symptoms appear later

% that answered

Yes

No

Hawaii
N = 523

Washington
N = 134

California
N = 221
If yes, what age should symptoms show by? *

- 18+ years:
  - California: 35%
  - Washington: 51%
  - Hawaii: 40%

- 10 - 18 years:
  - California: 43%
  - Washington: 52%
  - Hawaii: 46%

- 5 - 9 years:
  - California: 48%
  - Washington: 60%
  - Hawaii: 49%

- 6 months to 4 years:
  - California: 71%
  - Washington: 80%
  - Hawaii: 75%

* NBS for late onset disorders with known prevention or treatment
Do you want your newborn screened when there is NO KNOWN prevention or treatment for the disorder?

If symptoms appear before 6 months

% that answered

Yes

No

Hawaii
N = 518

Washington
N = 132

California
N = 209
Do you want your newborn screened when there is NO KNOWN prevention or treatment for the disorder?

If symptoms appear later

% that answered

Yes

No

Hawaii
N = 517

Washington
N = 132

California
N = 220
If yes, what age should symptoms show by? *

* NBS for late onset disorders with NO known prevention or treatment
Parental Attitudes Towards NBS for Late Onset Disorders Summary Findings

Parents generally support NBS for late onset disorders.

Parents are more supportive of NBS for disorders that show symptoms between birth and 4 years regardless of whether there is a known prevention or treatment.

Parents’ support of NBS for late onset disorders decreases as the age of onset of symptoms increases regardless of whether there is a known prevention or treatment.
Should the DOH contact you about follow-up services for your child?

Hawaii: 91% Yes, 9% No
Washington: 89% Yes, 11% No
California: 90% Yes, 10% No
How Often Do You Want to be Contacted?

- **Hawaii**: 52% (45% Once per year, 59% Once every 6 months)
- **Washington**: 65% (33% Once per year, 65% Once every 6 months)
- **California**: 36% (59% Once per year, 36% Once every 6 months)
How should we contact you?
HI = 68%
WA = 65%
CA = 62%

HI = 45%
WA = 49%
CA = 41%

HI = 37%
WA = 23%
CA = 40%

HI = 31
WA = 22%
CA = 38%
Program Contact Summary Findings

- Parents want to be contacted about once per year with reminders about follow-up.
- Parents prefer e-mail or mail for contact.
- Need to get parent’s e-mail and current mailing address if these methods are used to continue contact for follow-up.
Mahalo to our WSRGN Partners

Hawaii
Pauline Mui
Emi Morikawa
Michelle Takemoto
Lila Aiyar
Gwen Palmer
Jacquie Stock

Washington
John Thompson
Gauri Gupta
Nini Shridhar
Marcie Rider
Julie Walker

California
Lisa Feuchtbaum
Sara Goldman