Baby’s First Test: 5 Years of a National Educational Initiative

Jaclyn Seisman, MPH
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Who We Are:
The Newborn Screening Clearinghouse
The Newborn Screening Clearinghouse

*Increasing Newborn Screening Awareness and Education through Engagement*

- Newborn Screening Saves Lives Act 2008/2014
- One stop shop for newborn screening information and education
- Based on consumer focused newborn screening projects
Baby’s First Test houses the nation’s newborn screening clearinghouse. As the clearinghouse, Baby’s First Test connects parents and healthcare providers with extensive information and resources on newborn screening at the local, state, and national levels.

We Do This By:

- Training Videos/Webinars
- Continuing Education Opportunities
- Educational Resources
- Details on State Programs
- Information on 77 Conditions
Newborn Screening?

Many parents are unaware of the conditions included in screening, or that it varies from state to state. **Baby's First Test** brings together resources to help guide parents and health professionals alike.

What Your State Offers

Every state has its own Newborn Screening program. Learn about it.

Find a Condition

Get information about the 77 screenable conditions.
By The Numbers

26 Consumer Advocates
Since 2012, Baby’s First Test has trained 26 Consumer Task Force members across 18 states.

100,000 Content Pages
Baby’s First Test has over 100,000 pages of content, including information on 77 newborn screening conditions.

Over 1.1 Million Visitors
Since 2011, BabysFirstTest.org has had 1.1 million visitors with over 1.4 million sessions and more than 2.5 million page views.

100% Increase in Visits
With 100% increase in visits since 2014, this year brought nearly 622,000 visits from more than 520,000 users, averaging over 50,000 sessions per month and adding to the 1 million sessions on Baby’s First Test since our launch in 2011.
January 2012 – January 2016

1.1 Million Users

2.5 Million Page Views

1.4 Million Sessions

Nearly 50% of users are between 25-34 years of age
Traffic Breakdown

Top Referrers:
NIH’s Genetic Home Reference, BabyCenter.com, CDC and Facebook
Most Popular Content
1. Conditions Screened by State
2. Homepage
3. Screening Procedures
4. PKU
5. (other condition pages)

States
California, Texas, New York

Countries
United States (70%)
Also: UK, Philippines, India, Canada
Going Mobile

- Mobile traffic more than doubled each year
- In 2015, more than 50% of traffic came from mobile devices
  - Tablet (8%)
- Mobile and desktop users read the same content
- States and conditions were overwhelmingly popular

The Baby’s First Test mobile app launched in January 2016
Tell Us More: Stakeholder Evaluation of Baby’s First Test
2014 Evaluation of Baby’s First Test

- Purpose: to assess the program’s impact and to determine perceptions of the Clearinghouse as well as areas for further improvement.

- Four key groups were interviewed:
  1) Consumer Task Force members;
  2) Challenge Award recipients;
  3) Newborn screening thought leaders; and
  4) Newborn screening laboratory and follow up representatives

- Interviews were confidential and conducted by a third party evaluator

- 40 participants were recruited, representing a mix of parents, leaders from non-profit organizations, and lab and follow up professionals engaged in the newborn screening field
Key Findings

1. Overall, stakeholders found the Clearinghouse to be a helpful resource that supported local programs
   - Consumer Task Force
   - Challenge Awards

2. Benefit to newborn screening community/effective clearinghouse

3. Common use of Baby’s First Test:
   - To link to Baby’s First Test on own website
   - To check to see if information on Baby’s First Test if up-to-date
   - To compare newborn screening panels among states
   - To develop informational materials to give to families
Opportunities for Growth

Follow-Up Representatives

- Strategies for specific populations:
  - Low-income families
  - Non-English speakers
  - Rural audiences
  - No internet access
- Healthcare provider outreach
- Policymakers

State Representatives

- Communication with states
- Ensuring states link to Baby’s First Test

Thought Leaders

- More interactive space
- Focus on families whose babies have received a positive result
Going Forward
Analyzing User Survey

**User Satisfaction Survey**
- Launched user survey in October 2015
- Survey closed February 29, 2016
- Results will inform educational strategies and outreach

![Survey Results Graph](image)
Newborn Screening Education

Prenatal
- Tools: Brochures, State/National info sites, Social media, Strategies
- Prenatal visits
- Social media
- Advocacy orgs
- Insurance providers

Hospital
- Tools: Brochures, Bloodspot card, Newborn hospital channel, Strategies, Testing
- CCHD
  - Partners: Post-delivery, Nurses, Insurance
- Metabolic
  - Partners: Post-delivery, Nurses, Insurance
- Hearing
  - Partners: Post-delivery, Nurses, Insurance

Home
- Tools: Brochures, Discussion forums, State/National info services, Social media, Strategies
- Social Media
- Partners
- Advocacy Orgs

Abnormal Result
- Tools: Notification phone call, State/National info sites, Doctor’s records, Strategies
- Accurate info
- Accurate explanations by practitioners
- Referrals to advocacy/testing org
- Partners
- Doctors/Nurses
- APHL
- Advocacy orgs

Positive
- Tools: Brochures, Medical info sites, Discussion forums, State/National info sites, Social media, Strategies
- Social media
- Accurate info
- Referrals to advocacy orgs
- Partners
- Genetic counselors
- Doctors/Nurses
- Advocacy Orgs
- Insurance providers

Negative
- Tools: State/National info sites, Brochures, Medical info sites, Discussion forums, Strategies
- Social media
- Accurate info
- Referrals to advocacy orgs
- Partners
- Advocacy Orgs
- Doctors/Nurses
- Genetic counselors

Healthy Baby Visits
- Tools: Brochures, State/National info sites, Social media, Strategies
- Social media
- Partners
- Doctors/Nurses
- Insurance providers

Confirmatory Testing
- Tools: Genetic counselors, Doctors/nurses, Strategies
- Accurate info
- Referrals to advocacy orgs
- Partners
- Advocacy Orgs
- Testing companies
- Genetic counselors
- Doctors/Nurses

Public Knowledge
- Baby’s First Test/Other newborn info sites
- Doctors/Nurses
- Genetic Counselors
- Family/Friends
- People with the same health condition
- Newspapers/Online news sources
- Social Media
Baby’s First Test State Pages

2011

<table>
<thead>
<tr>
<th>Draft Pages Created Based off of State NBS and Genetic Laws and Policies</th>
<th>Draft Document Sent to State Program</th>
<th>Edits Incorporated</th>
<th>New Draft Shared with State</th>
</tr>
</thead>
<tbody>
<tr>
<td>Published Online</td>
<td>Send Annually to State for Review with Noted Discrepancies from Other National Resources</td>
<td>Technical Changes</td>
<td>Edits Incorporated Once Confirmed, Corrected and Resent to the State Programs</td>
</tr>
<tr>
<td>On-going</td>
<td>Non-technical Changes</td>
<td></td>
<td>Publish</td>
</tr>
</tbody>
</table>

Process for Year Round Changes in State Condition Panels

- Program Staff Notified of Condition to be Added (Conferences, Presentations, Google Alerts)
- Contact State Program for Verification of Implementation Date
- Email or Call State One Week Prior to Implementation Date to Confirm
- On Date as Provided by State, Add Condition to State Page
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Learn More:

Visit us in Booth #209
Poster #50: Bridging the Language Gap: Creating Culturally Competent Newborn Screening Education for Spanish-Speaking Populations