




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

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Who We Are:
The Newborn Screening
Clearinghouse

The Newborn Screening Clearinghouse

*Increasing Newborn Screening Awareness and Education through **Engagement***



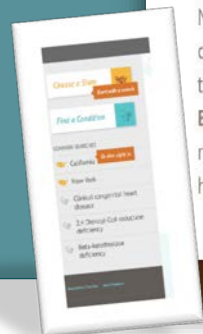
- Newborn Screening Saves Lives Act 2008/2014
- One stop shop for newborn screening information and education
- Based on consumer focused newborn screening projects

Baby's First Test: What We Do

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



A screenshot of the Baby's First Test website homepage. The header features the logo and navigation links: 'About Newborn Screening', 'What to Expect', 'Living With Conditions', 'Health Professionals', and 'Blog and News'. The main content area has three columns: 1) 'Newborn Screening?' with a text block and a 'Choose a State' dropdown; 2) 'What Your State Offers' with a map of the US and a 'Choose a State' dropdown; 3) 'Find a Condition' with a magnifying glass icon and a 'Type a Condition' input field with a search arrow.



Your State

Find a Condition



En Español

About
Newborn Screening

What
to Expect

Living
With Conditions

Health
Professionals

Blog
and News

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.

- Select State -



Find a Condition

Get information about the 77 screenable conditions.

Type a Condition



Get The Facts

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

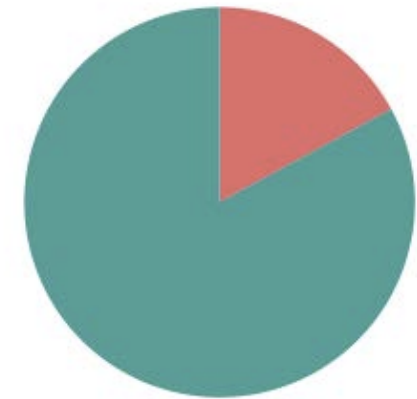
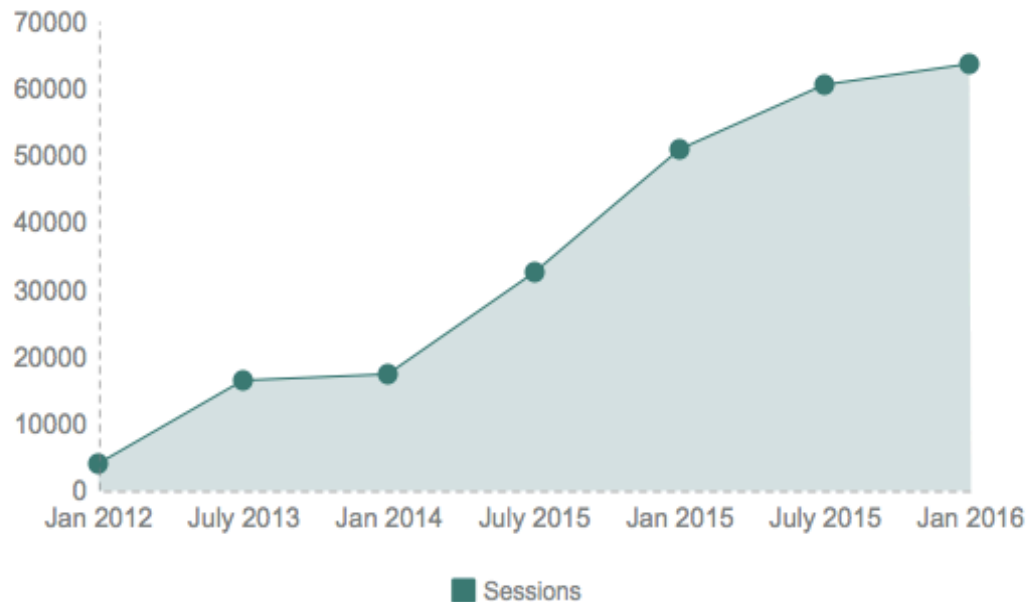
Since 2011, BabysFirstTest.org has had 1.1 million visitors with over 1.4 million sessions and more than 2.5 million page views.

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



■ Returning Visitor (17%) ■ New Visitor (83%)

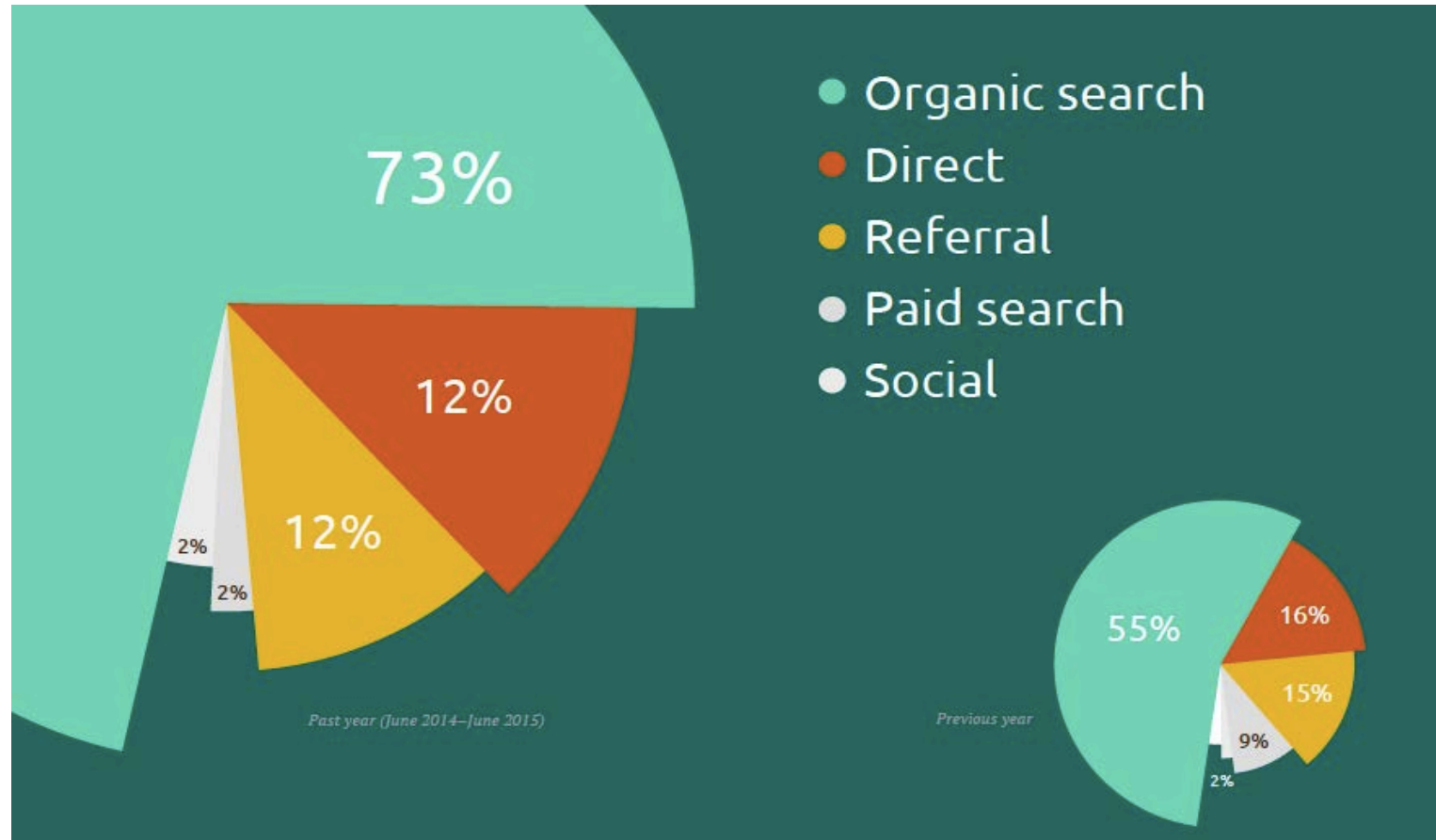
**1.1 Million
Users**

**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

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



Conditions

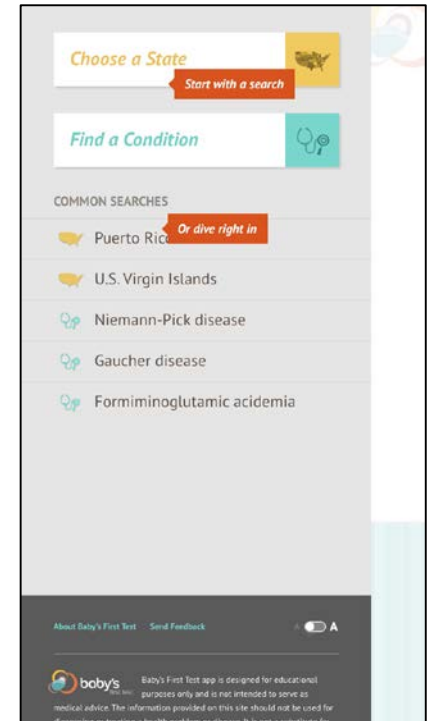
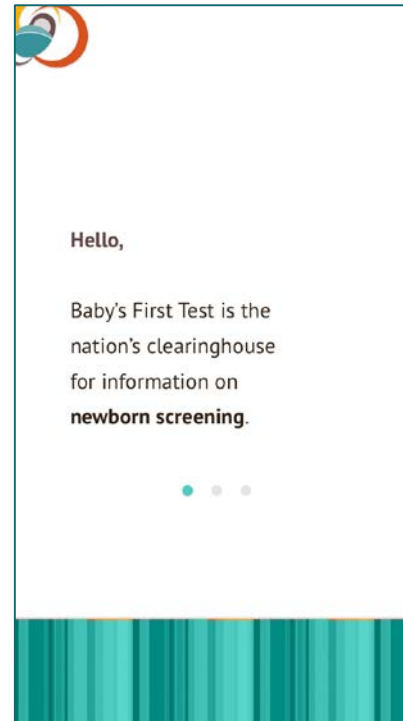


States

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 is 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

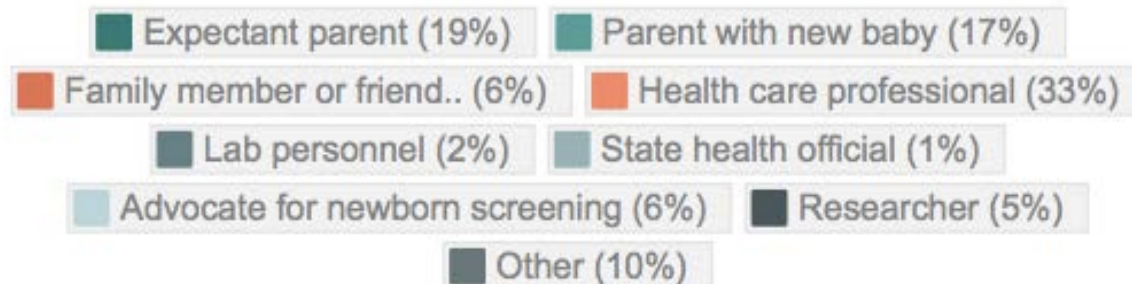
The background is a solid teal color with a grid of small, lighter teal dots. The dots are arranged in a regular pattern, with a larger gap in the center where the text is located.

Going Forward

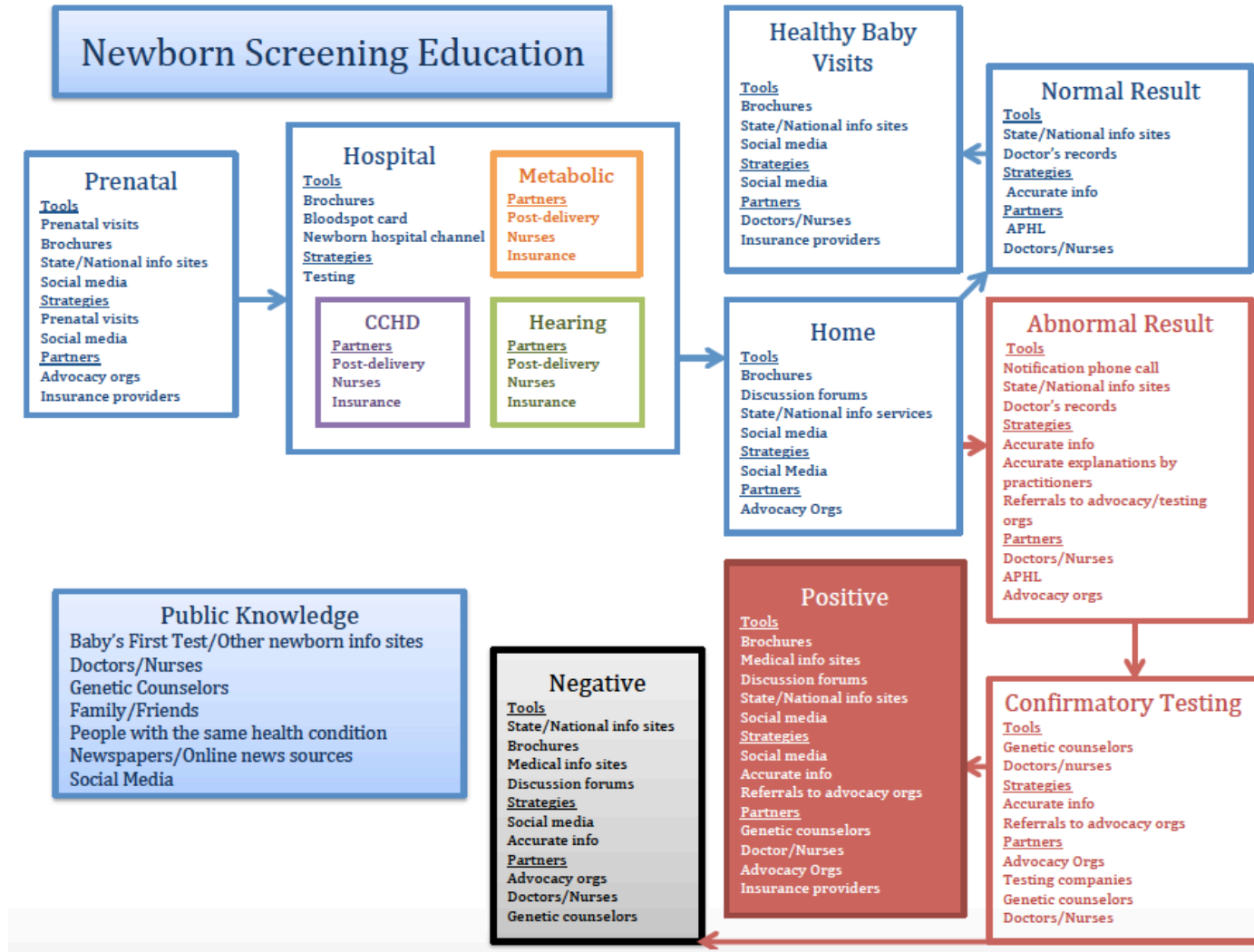
Analyzing User Survey

User Satisfaction Survey

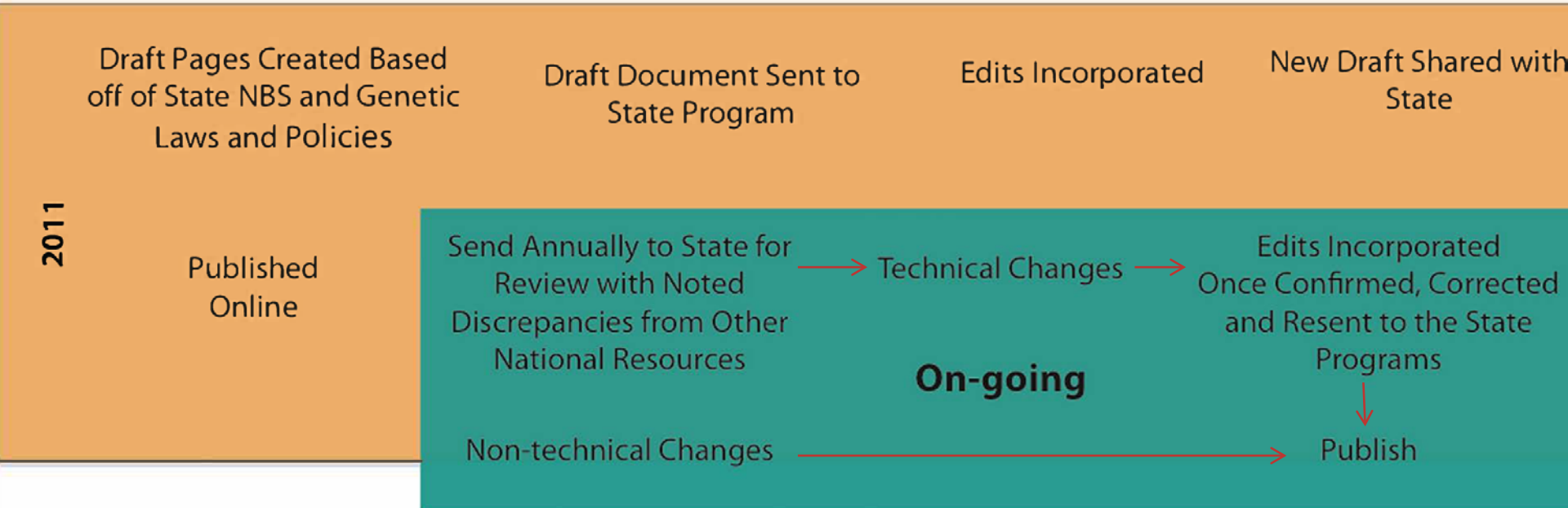
- Launched user survey in October 2015
- Survey closed February 29, 2016
- Results will inform educational strategies and outreach



Newborn Screening Education



Baby's First Test State Pages



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

Acknowledgements:

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Blenderbox, Inc

Learn More:

Visit us in Booth #209

Poster #50: Bridging the Language Gap: Creating Culturally Competent Newborn Screening Education for Spanish-Speaking Populations



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