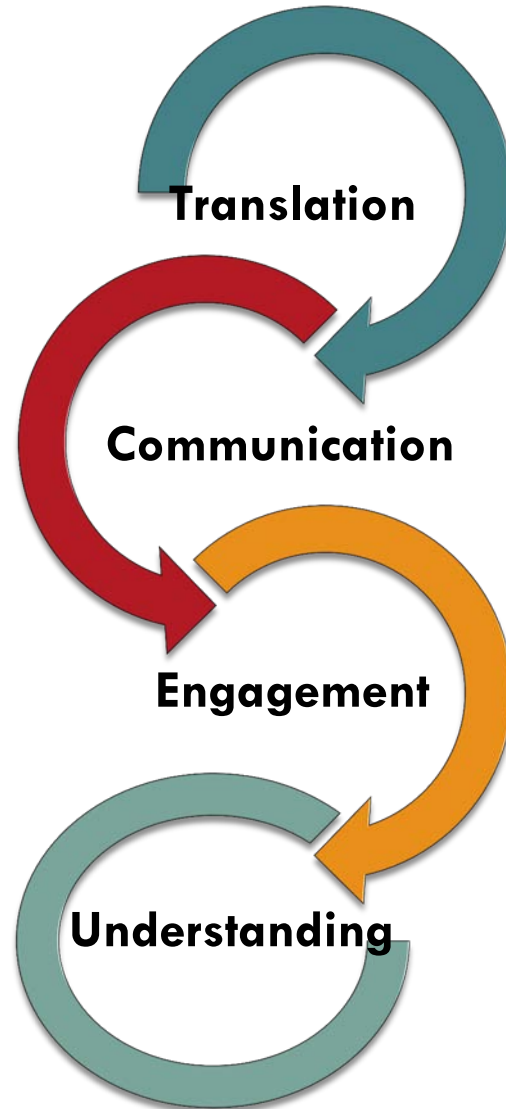


Raising Awareness in Newborn Screening: Strategies and Updates

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What Do We Mean By Education?



What we know

NBS Communication Challenges

- New technology/rapidly changing environment
- State programs differ (disorders screened, info given, process of reporting results)
- Parents/ public lack basic knowledge
- Hospital birth visit a “fog” for most parents
- Primary providers may lack up-to-date information, patient education materials, time
- Best practices yet to be identified

<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/meetings/fourth/informingparents.pdf> T. Davis 2005



7

Things Parents Want to Know About Newborn Screening:



THE HEALTH PROFESSIONAL'S GUIDE FOR BRIEF DISCUSSION WITH PARENTS.

1. All newborn babies are required by the State to get tested for some rare disorders before they leave the hospital.
2. Babies with these disorders may look healthy at birth.
3. Serious problems can be prevented if we find out about the disorders right away.
4. To do the test, a nurse will take a few drops of blood from your baby's heel.
5. Your baby's doctor and the hospital will get a copy of the test results. Ask about the results when you see your baby's doctor.
6. Some babies will need to be retested. If your baby needs to be retested, you will be notified. It is very important to get retested quickly.
7. Talk to your baby's doctor if you have questions. The Web site on the back of the brochure also has good information.



Stats

- 87% of U.S. adults use the internet (January 2014 survey).
- 72% of internet users say they looked online for health information within the past year.
- 70% of U.S. adults got information, care, or support from a doctor or other health care professional.
- 31% of cell phone owners, and 52% of smartphone owners, have used their phone to look up health or medical information.
 - This finding is of particular interest to those interested in trends related to young people, Latinos, and African Americans, since these groups are significantly more likely than other groups to have mobile internet access.



Stats (Con't)

- 86% of online women look for health information, compared with 73% of online men.
- 85% of American adults own a cellphone
- 58% of Americans use social media

Public Health Campaigns

- Folic Acid: \$2,000,000 (2001)
- Breastfeeding: \$80,000,000 in peer counseling program (2010)



Health Literacy

- “Obtain, process, and understand basic health information” IOM
- Cultural Context
 - ▣ Linguistic, regional, experience-based
- Education → Communication



Where are People Seeking Information?

- Family/ Trusted Communities
 - Religious
 - Social
- Online
 - BabyCenter
 - The Bump
 - What to Expect When Expecting
- Physician/ Healthcare Provider/ Prenatal Classes
- Word of Mouth



Messaging

- Identify the audience
- How to get their attention
- Get them to listen to the message
 - ▣ Hear/ See it multiple times (7x)
 - ▣ Understand/ Accessible
 - ▣ Believe it/Complementary to other information
- What is in it for me?

- (adapted from Church, T. *Strategies for Successful Public Health Messaging*
<http://www.nwcphp.org/documents/training/hot-topics-1/successful-messaging-notes>)



Condition specific (SCID)

- Video, family experience
<http://primaryimmune.org/idf-advocacy-center/>
- Brochures and hand-outs

Newborn Screening for Severe Combined Immunodeficiency (SCID) and Conditions Associated with T Cell Lymphopenia

Babies can look healthy at birth and still have health problems that need to be recognized and treated. For this reason your baby had routine newborn screening tests done in the hospital before discharge. A few drops of blood were taken from your baby's heel and tested for a number of disorders. One of the tests performed is to detect problems with the immune system. Your baby had a result on this test that was either abnormal or did not give a clear result, and therefore additional testing needs to be done as soon as possible.

What Does An Abnormal Screening Test Mean?

The screening test shows that your baby may have a low number of a type of white blood cells called "T cells." Low numbers of T cells can be associated with a genetic condition called Severe Combined Immunodeficiency or SCID (pronounced "skid") which would place your baby at extreme risk for serious, life-threatening infections. The screening test alone cannot be used to make a diagnosis of SCID, which is why a new blood test is needed to determine if your baby has a life-threatening immune disorder. You will receive instructions from your medical provider or your State newborn screening program about getting a new specimen without delay.



What is SCID?

SCID is a set of more than a dozen different genetic disorders, all of which result in a failure to develop T cells and inability to make protective antibodies. Most newborns with SCID appear healthy at first because the mother's immune system protects them from infections for the first few weeks of life. However, without treatment, even common infections can be life threatening. If your baby has SCID a treatment plan can be started to help prevent infections and establish a functioning immune system.

What Other Immune System Problems Could My Baby Have?

In addition to SCID, the screening test also picks up other conditions associated with low T cells. These are often not as severe as SCID, but are important to find out about and treat. Although these are immune diseases they are not related to HIV or AIDS and are not infectious.

How Common is SCID?

In past years, it was believed that the incidence for babies born each year with SCID was 1 in 100,000. New data available from states that have initiated newborn screening programs for SCID suggest that the incidence may be somewhat more common.

How are SCID and Other Conditions Associated with T cell Lymphopenia Treated?

The most effective treatment for SCID is a bone marrow transplant. This treatment can be done soon after birth and has a high success rate when done in the first few months of life. Some of the other conditions associated with low T cells will also be treated with bone marrow transplant, while others may be most appropriately treated with other therapies. A diagnostic evaluation by an immunologist will determine what kind of treatment your baby needs.





Life of Riley

August 8, 2014 · 🌐

One year ago today I woke up dreading a phone call...I knew it was coming. Late in the day it was confirmed...Riley had SCID. No fluke, no false positive and no immune system.

Today I woke up to a sick baby. That's right. Our first illness outside hospital walls happened today. Poetic? Ironic? Terrifying? Uh huh.

According to the doctors her little body should be able to fight this off all on it's own...it may take her longer and hit her harder but she should be just fine. ... [See More](#)



👍 Like 💬 Comment ➦ Share

182 people like this.

Top Comments ▾

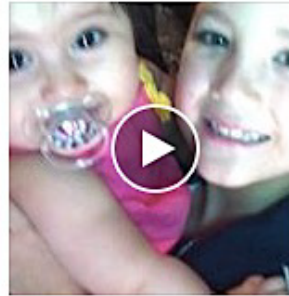


Mountain States Genetics Regional Collaborative

👍 Like Page ▾

July 14, 2014 · 🌐

Do you know what [#SCID](#) is? This video explains it well from a family in California. Many of the states in our region are screening newborns for SCID. Can you name which ones are? <https://www.youtube.com/watch?v=nYqoEbY6JSo>



SCID Newborn Screening in California

Annalou's family talks about how newborn screening for Severe Combined Immune Deficiency (SCID) in California changed their lives and how important it is to ...

YOUTUBE.COM

The Centers for Disease Control and Prevention says that about 40 to 100 newborns in the United States are diagnosed with SCID every year. The babies appear normal at birth but can develop life-threatening infections within a few months.



Like Comment



Contemporary Pediatrics

The US Food and Drug Administration (FDA) has cleared for marketing the first screening test for severe combined immunodeficiency (SCID) in newborns.

Album: Timeline Photos

Shared with: 🌐 Public



State specific-Minnesota

- Billboards
- Infographics
- Webinar

<https://youtu.be/GUm8DcAC6sc>

After Newborn Screening


What happens to leftover blood spots and results?

Parents can choose what happens with the leftover blood spots and results.  Each spot is smaller than the size of a dime. 

Option A: The blood spots and results can go into safe storage at the Department of Health. This is what normally happens. **You do not have to do anything** to choose this option.

Option B: The blood spots and results can go into safe storage, and they also can be used for research to help improve the public's health. To choose this option, **you have to give permission by signing a consent form**. If you do not give permission, the blood spots and results will **never** be used for research.

Option C: You can ask the Department of Health to destroy the blood spots and results. To choose this option, **you have to fill out a destruction request form**. If you choose this option, blood spots will no longer be available for testing if you or your doctor needs them.

If you choose **Option A** or **Option B**, you can change your mind and choose a different option at any time. Just contact the Department of Health. 


Ask your doctor, nurse, or midwife for the form you need for **Option B** or **Option C**. Or you can find forms on the website at the bottom of this page.

There are a few reasons why it is helpful to keep leftover blood spots and results at the Department of Health. These reasons include:

Testing Improvement: To make sure we find all babies who might have one of these health problems, we need to make sure that our tests and equipment are working the way they should. This process is called quality control or assurance.

Family Needs: Some families ask for them later to do testing if their child gets sick. Looking at blood spots can help give clues to whether something at birth made the child sick.






New Test Development: We use them to help develop new tests so that babies with other health problems can be found and treated early too. All blood spots used to make new tests are de-identified, meaning the baby's name, date of birth, or any other identifying information is not attached to the blood spots.

Want to know more? 

Call us: 1-800-664-7772
Email us: health.newbornscreening@state.mn.us
Visit us: www.health.state.mn.us/newbornscreening

Newborn Screening Program
601 Robert St. N., St. Paul, MN 55155

DP 54359
REV 05/2015



State Specific - Texas

- Collection form
- Webpage
 - New policies and effective dates
 - Specimens collection video



What Do We Need In the ~~Future~~ Today?

- Re-Establish Value
- Consistent Message multiple places, multiple sources
- Embed in established communications channels
 - Go Find Information - Brochures, static sites
 - Information Finds You -New Technologies: apps, mobile friendly sites, texts
- Is there a shared message around NBS? Around the addition of new conditions?



Update

Newborn Screening Clearinghouse

Baby's First Test

- US Newborn Screening Clearinghouse
- Newborn Screening Saves Lives Act 2008/2014
- Health Resources and Services Administration Funded
- Based on Consumer Focused Newborn Screening Projects (2007-10)

Baby's First Test informs and empowers families and healthcare providers throughout the newborn screening experience. By increasing awareness, we offer millions of newborns and their families a chance at a healthy start.



Web Stats and Developments

Sections

- About Newborn Screening
 - ▣ Facts, Resources, RUSP
- What to Expect
 - ▣ Process, Results, Follow Up, Blood Spots
- Living With Conditions
- Health Professionals
- Blogs and News
- What Your State Screens For
- Find A Condition

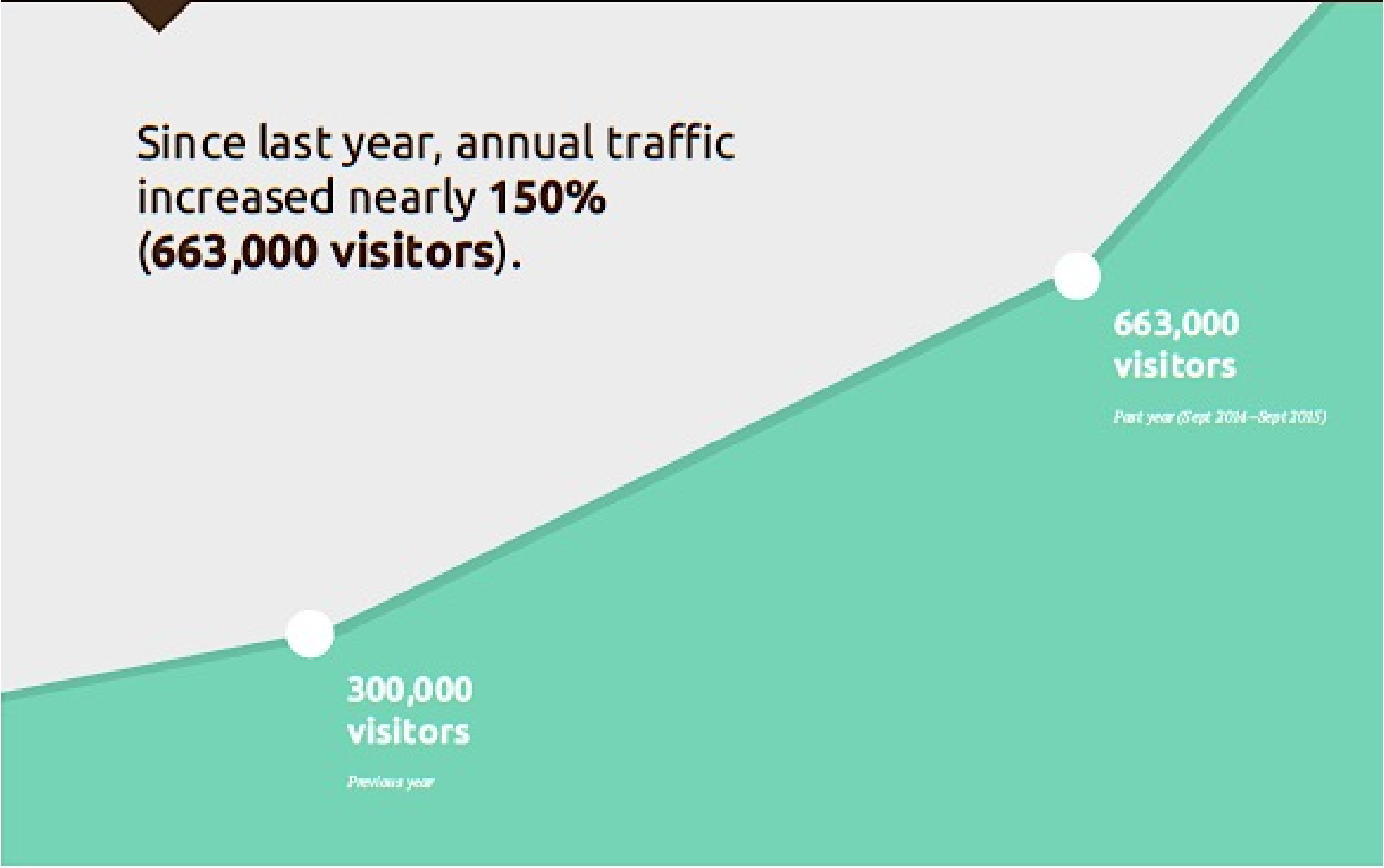


Overall traffic

Since last year, annual traffic increased nearly **150%** (**663,000 visitors**).

**300,000
visitors**
Previous year

**663,000
visitors**
Part year (Sept 2024–Sept 2025)



Stats from September 2011 - September 2015

● Sessions



Sessions

1,109,815



Users

914,029

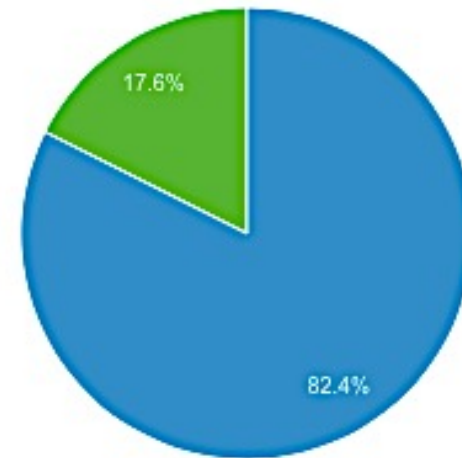


Pageviews

1,976,394



■ New Visitor ■ Returning Visitor



Most Popular

Most Popular Content

1. Conditions Screened by State
2. Homepage
3. Screening Procedures
4. PKU
5. (other condition pages)

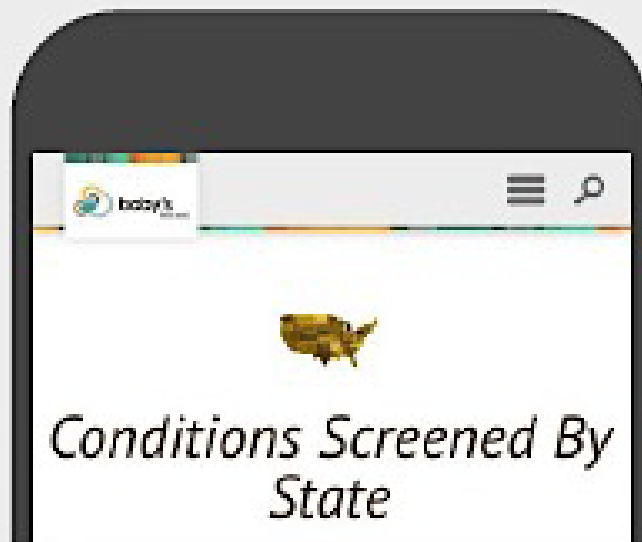
States

California, Texas,
New York

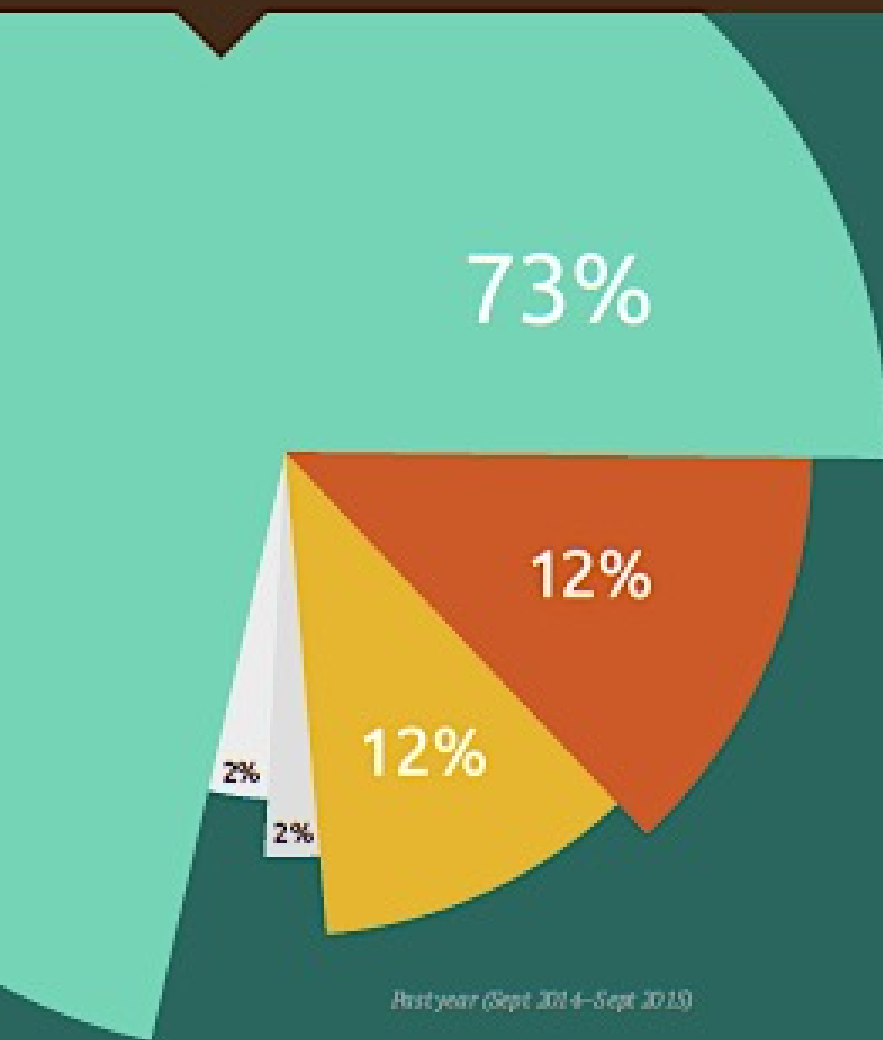
Countries

United States (70%)

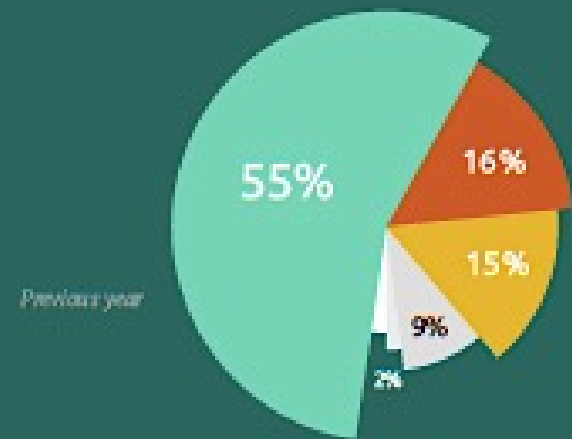
Also: UK, Philippines,
India, Canada



Traffic breakdown



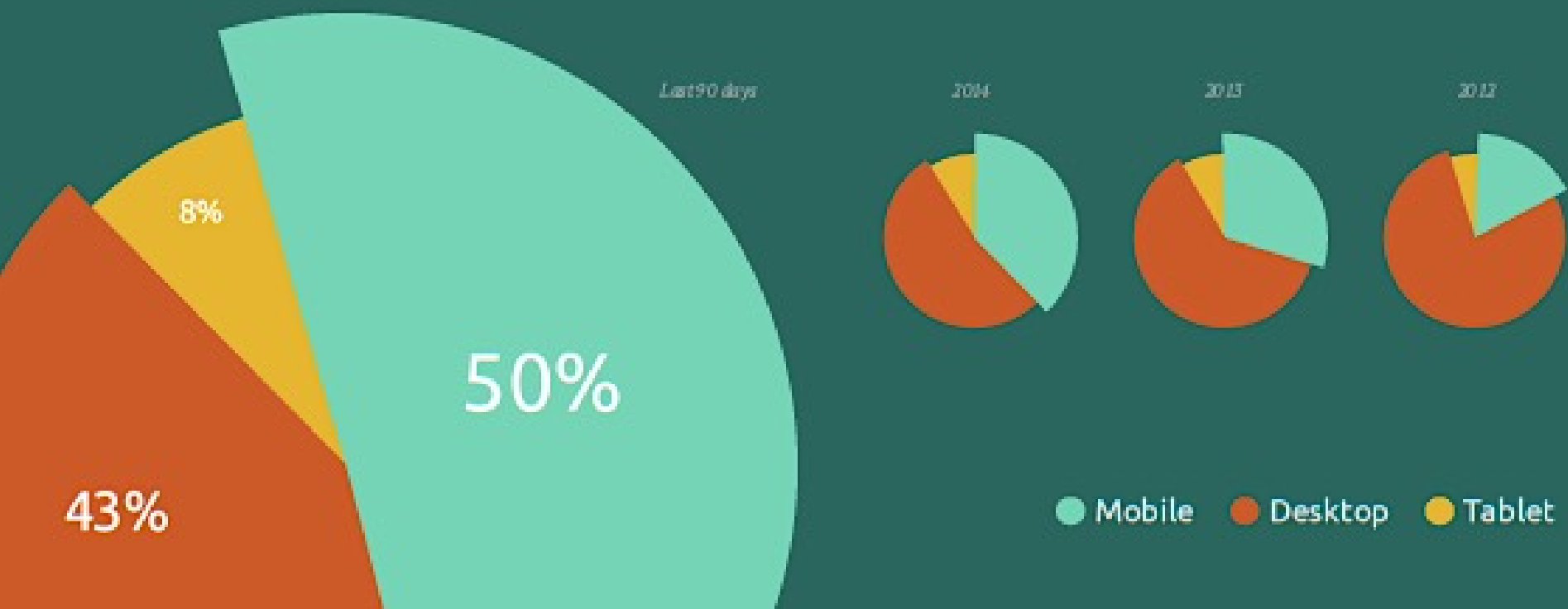
- Organic search
- Direct
- Referral
- Paid search
- Social



App Development and Site Refresh

Devices

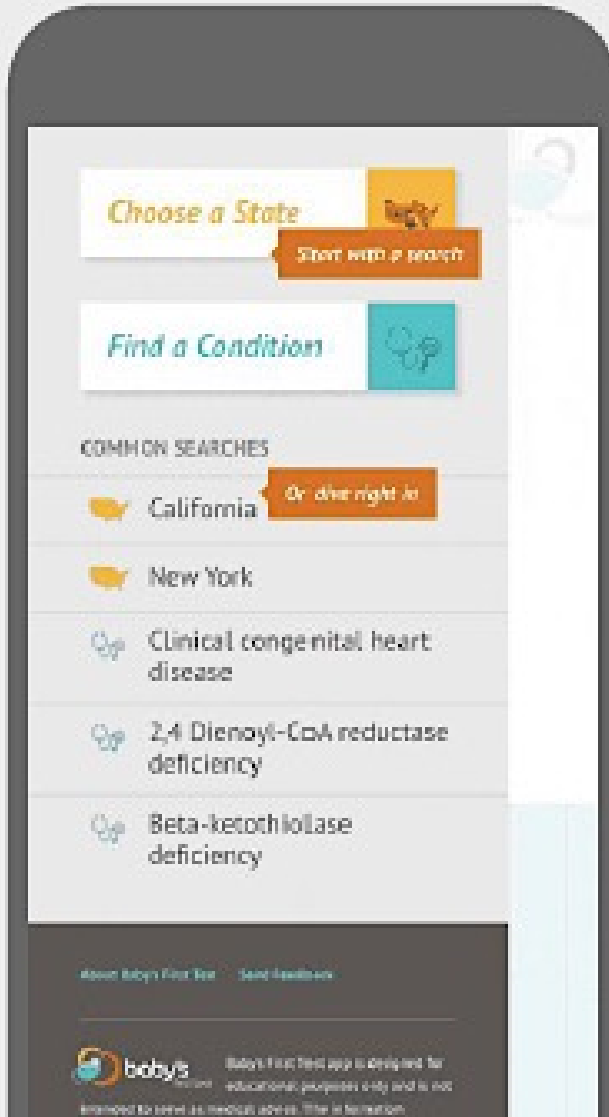
Mobile continues to grow. At the start of 2015, it overtook desktop traffic.



Observations

- Mobile traffic more than doubled each year
- Mobile and desktop users read the same content
- States and conditions were overwhelmingly popular
- Longform pages needed fresh design

Design



Navigation lets
you search with
ease

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

Newborn screening is just one of many things that happen in the first few days after a baby is born. The following information can help prepare expecting parents for the newborn screening process and answer common questions, such as: What should I do Before Birth? What are the Screening Procedures? How should I respond to the Results? What are the Screening Outcomes? What happens to the Blood Sample?

WHAT TO
EXPECT



La evaluación del recién nacido

Hay muchos padres que no saben sobre las condiciones de las evaluaciones de recién nacidos. También, no los saben que condiciones en la lista cambian en cada estado. BabysFirstTest (La primera prueba de su bebé) ofrece recursos educativos para ayudar los padres y médicos.



En su estado

Cada estado tiene su propio programa de evaluaciones de recién nacidos.

- Select State -



Buscar condiciones

Obtenga información sobre 77 condiciones detectable.

Type a Condition



Obtenga los detalles

Las evaluaciones de recién nacidos son algunas de las cosas más importantes en el primer día después del parto. Información en este sitio puede ayudar padres y infórmelos sobre los procesos de las evaluaciones de recién nacidos. Qué debo hacer antes del nacimiento? Qué son los pasos de la evaluación de recién nacido? Cómo debo responder a los resultados de la prueba? Y qué va a pasar a las gotas de sangre del talón de mi bebé?

Que Esperar

Baby's First Test Initiatives

*Increasing NBS Awareness and Education
through **Engagement***

WikiNewborn Screening Forum/Public Square & Infowebinars

- Create virtual public square where NBS community can convene and discuss issues/current events in real time
 - ▣ Consumer led/centric approach
 - ▣ Three virtual 'town halls' on range of topics, including policies and practices
- Bimonthly info webinars
 - ▣ Information sharing & training
 - ▣ Specific interest groups & public



Other Activities

- Online survey conducted by NORC on use of website
 - ▣ Launched last week
 - ▣ Cognitive testing
- Identify, review, and promote culturally sensitive education and decision making tools
- Add CEU modules to healthcare provider section
- Review messaging platforms
- Easy-to-navigate, online module for NBS resources, publications, fact sheets, videos, etc.
- Expand content on BabysFirstTest.org
- Increase information sharing with trusted sources



Who are the Stakeholders/ Key Audiences?

- General Public
- Parents of affected children
- Parents of unaffected children
- Healthcare Providers
- Policymakers
- Industry

All these stakeholders have a low understanding of genetics and screening



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 - Stacy Hines-Dowell, DNP, APNG (Co-Chair)
 - Blenderbox, Inc





Thank you

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