CAMPAIGN SUMMARY

Of the more than four million babies born in the U.S. each year, newborn screening saves the lives of more than 12,000—from death or from a lifetime of intellectual or physical disability. This year newborn screening celebrates its 50th anniversary as a state-initiated, automatically-delivered public health program. To mark this achievement and to raise public awareness about the importance of newborn screening to healthy communities, the Association of Public Health Laboratories (APHL) and the Centers for Disease Control and Prevention (CDC) have launched a national public awareness campaign.

The campaign aims to reach parents, their families and the physicians, nurses and midwives who provide care before, during and after a child’s birth. The goal is to raise parents’ awareness about newborn screening and to increase parents’ and healthcare providers’ understanding of the scope and effectiveness of newborn screening, and the importance of follow-through when treatment is necessary for identified newborns.

An important element of the campaign strategy to reach families is an exhibit that tells the story of newborn screening. The exhibit, which reveals the scientific discoveries that enable mass, rapid and accurate testing of the newborn population, and recounts the experiences of families touched by early detection of a condition, will travel to 13 state public health laboratories this year. State public health laboratories are responsible for analyzing 97% of all newborn screening tests sent to them from hospitals, usually within 48 hours of a baby’s birth. This vital service provides doctors and families with early, critical information to improve—and save, in many cases—the lives of children with rare but serious health conditions.

In conjunction with the exhibit, the 13 state public health laboratories will invite families and local school students to a “Day at the Public Health Lab” where they will be invited to live some of what state lab scientists experience in a day of newborn screening. Visitors will learn about the advanced analytic technologies used to detect newborn screening conditions and the race to respond when a baby screens positive for a condition. They may also explore other life-saving public health laboratory services and related scientific concepts.

Additionally, state executives and legislatures in the 13 participating states will be offered the opportunity to host the newborn screening exhibit at their state houses. As each state funds its own newborn screening program, awareness of the program’s importance to family and community health and its role in reducing future healthcare costs, are important to policymakers. A brochure examining policy issues will be available at the exhibits. Later this year, an illustrated newborn screening book will be mailed to state governors to reinforce these messages.

The 50 Years of Saving Babies Campaign was rolled out in New York City in October with public service announcements (PSAs) on the CBS jumbotron screen in Times Square. The campaign officially launched during New Year’s week with a second jumbotron PSA. The two 15-second spots ran in sequence 75 times per day from late October through January 11 over an 18-hour daily schedule.

For campaign information and materials go to www.50yearssavingbabies.org. Use #newbornscreening on Twitter for updates on the campaign and to join the conversation on newborn screening.
NEWBORN SCREENING: A 50-YEAR HISTORY OF LIFE-SAVING SCIENCE

1950-1963: A parent’s determination leads to breakthrough
When Dr. Robert Guthrie had a son with intellectual disability, the researcher began to focus on finding causes and cures for mental disorders. This led Guthrie to explore a condition called phenylketonuria, or PKU. Babies with this metabolic condition would appear healthy for days or even years after birth—and suddenly be struck with severe disabilities. A special diet begun in the first days of life could prevent the damage.

If every infant could be tested for PKU at birth, thousands could be saved—so Guthrie invented a screen that would be accurate, efficient and inexpensive enough to use on every newborn.

Today, Guthrie’s method is still the basis of newborn screening: About 24 hours after birth, an infant’s heel is pricked to collect a few drops of blood on special filter paper. This specimen is screened, usually in a public health laboratory, for dangerous conditions.

1963-1999: Innovations detect more conditions
Massachusetts, Delaware, and Oregon became the first states to screen every baby for PKU. In 1973, Dr. Michael Garrick developed a screen for sickle cell anemia, enabling early treatment to avoid infection. In 1974, Dr. Jean Dussault of Quebec piloted his test for congenital hypothyroidism, a condition found in about 1 in 4,000 newborns, which can cause severe disability.

In the 1990s, lab technology called tandem mass spectrometry reduced screening time from days to minutes—and made it possible to include additional rare conditions. At the same time, the healthcare system was rapidly changing.

While lifesaving, these advances created new challenges for states, labs and healthcare alike. Resources and technology capacities varied widely around the nation. One state might screen for four conditions while a neighbor screened for 24. Newborn screening wasn’t reaching its full potential to save lives and prevent disability.

1999-today: Getting the best to every baby
Over the first decade of the new century, public health labs, the CDC and the lab industry worked together to ensure quality and implement new technologies. Physicians and nurses, hospitals and the state health departments established systems to protect every baby. Parents and advocacy groups sought funding to improve programs and education.

Guided by the federal Health Resources and Services Administration, APHL joined other lab and medical groups as well as advocate groups to guide expanded newborn screening toward nationwide excellence. In 2002, the American College of Medical Genetics led a multi-year, multi-stakeholder project to develop the Recommended Uniform Screening Panel, a list of conditions for which every state should screen newborns. In 2003, HRSA launched the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children, whose collaborative of experts and parents established and now maintains a transparent process for those who seek to add conditions to the list.

Today, most states screen for a minimum of 29 conditions, and many screen for more. Although lab science, healthcare and policy grow more complicated daily—with personalized medicine and DNA testing presenting new issues—the goal of newborn screening remains as simple as a drop of blood on a piece of paper: save babies.
PUBLIC HEALTH LABORATORIES

When health risks emerge or re-emerge, public health laboratories analyze the threat, provide the answers needed to mount an effective response and act to protect the public in collaboration with other decision makers. Unlike private medical laboratories that perform tests to diagnose illnesses and conditions afflicting individual patients, public health laboratories safeguard entire communities. In one way or another, their work affects the life of every American.

What are public health laboratories?
Public health laboratories are state and local governmental health labs that conduct complex testing to protect their communities from diseases and other health threats. Such testing requires highly trained staff, sophisticated instrumentation and specially-designed facilities. There are approximately 300 public health laboratories in the U.S.; in many cases, the services they provide are unavailable elsewhere in their jurisdiction.

What is the critical role of a public health laboratory?
Public health laboratories serve as the nation’s early warning system for diseases and other health hazards. They protect their community’s health by monitoring continuously for diseases and other health hazards.

How do public health laboratories interface with federal health agencies?
Public health laboratories work very closely with the Centers for Disease Control and Prevention (CDC) and other federal health agencies. In many respects, they function as the “CDC laboratory” within their state or community.

In collaboration with CDC and the World Health Organization, for example, public health laboratories monitor influenza viruses to identify changes that can affect their transmissibility and severity and their response to anti-viral drugs.

How do public health laboratories respond to emerging health threats?
Public health laboratories are the nation’s laboratory first responders. During the outbreak of 2009 H1N1, for example, public health laboratories tested over 100,000 specimens in one month (almost as many as they normally test in one year). In addition, public health laboratories:

- Screen 97% of the babies born in the U.S. for potentially life-threatening metabolic and genetic disorders.
- Monitor communities for pathogens that spread in food or through contact with people or animals.
- Perform almost all testing to detect and monitor newly emerging infectious diseases like West Nile virus, SARS and H1N1 influenza.
- Test drinking and some recreational water for bacteria, parasites, pesticides and other harmful substances.
- Rapidly identify suspect agents, as in 2012 when the Colorado public health laboratory detected a case of bubonic plague in a seven-year-old girl who recovered from the potentially fatal disease with prompt treatment.

Newborn Screening: 50 Years of Saving Babies’ Lives

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If public health laboratories are so vital to safeguarding the public’s health, why are they so poorly funded?

Federal funding for public health laboratories goes up when a crisis hits and drops as soon as it is over. But laboratory capacity cannot be built overnight when a crisis hits; it takes time to locate and hire a molecular scientist, or to acquire and validate new laboratory equipment. Moreover, federal funding for public health laboratories has been scattered among programs for influenza, HIV/AIDS, STDs and other diseases. It’s not possible to maintain a national laboratory system with fragmented and episodic funding.

Meanwhile state and local funding for public health laboratories has been slashed as a result of the economic downturn. State laboratories saw their budgets cut by an average of $405,000 each (or $39 million nationally) in 2008, and cuts have only deepened in subsequent years.

Do public health laboratories have an adequate IT infrastructure for transmitting test results and other health data?

No. Data critical for national disease control is being delayed by outmoded, laborious reporting methods. Presidential Directive #21 calls for a networked system to facilitate data exchange among public health laboratories, health officials and clinicians, but no such system yet exists.

With an electronic system for exchange of test results, data would travel instrument-to-instrument without human intervention. APHL is building infrastructure and systems for the exchange of lab data through the Public Health Laboratory Interoperability Project (PHLIP) and other informatics initiatives.

Why are there concerns about the staffing level at public health laboratories, and what are the potential ramifications of this on the public's health?

Despite increased demands, public health laboratories lost 10% of their workforce over the five years, 2007 - 2011, and more cuts are anticipated. (APHL National Laboratory Capacity Assessment Survey, 2011) To compound this challenge, labs are losing staff to better-paying clinical or research labs, and their leadership is retiring or leaving the public sector at a time when few professionals with the requisite experience and credentials are available to replace them.

More Information

For more information on the Association of Public Health Laboratories, contact Jody DeVoll, 240.485.2753, jody.devoll@aphl.org; check our website www.aphl.org; read our blog www.aphiblog.org and follow us on Twitter twitter.com/APHLNews.

To find out more about APHL, view our brochure.
TIPS FOR PROMOTING THE 50TH ANNIVERSARY OF NEWBORN SCREENING

Media

Work with your agency’s public information officer (PIO) to place stories about your newborn screening program in local parenting and family blogs or in the local newspaper. (See example from Nevada.) Invite reporters to tour the newborn screening laboratory and interview a family whose child is alive and healthy thanks to screening. For background information and resources, direct media to APHL’s 50th Anniversary website. Story concepts could include:

- A family’s experience from screening through confirmation, treatment and follow up.
- Profile of newborn screening laboratory director or other newborn screening scientist. (See example from New York.)
- First baby detected with a condition added to state’s newborn screening panel.
- Introduction of laboratory technology that extends, expedites or otherwise improves detection of newborn screening conditions.
- Applied research to advance screening of genetic or metabolic conditions in newborns.

Web & Social Media

- Feature news and family stories from your newborn screening program on state health department and public health lab websites. Ask the state health director to write a blog post about the 50th Anniversary and the lab’s role in protecting babies’ health. (See example from Arizona.)
- Ask newborn screening staff to make a two-minute video about their experience detecting a child with a newborn screening condition. What happened? How did they feel? Did the experience change them in any way? Staff will generate many other ideas for inexpensive video productions, just remember to keep the videos short.
- Post media coverage and news of your newborn screening program on the state health agency’s Facebook page and Twitter feed, if available. Ask lab staff to share news via their personal Facebook and Twitter accounts. If sharing health agency news via social media is not prohibited in your state. Find content on APHL’s Facebook and Twitter sites.
- Share links from stories on the APHL blog of families whose lives have been affected by newborn screening or, in some cases, the absence of it.
- Use the hashtag #newbornscreening when you tweet about the campaign.
- Share linked images from APHL’s newborn screening Pinterest board and connect to an online network of exponents of newborn screening.

FAMILY SPOKESPEOPLE

The following families have agreed to make themselves available for media interviews.

Kevin Alexander
See Kevin’s Video
Adult living with PKU, advocate and videographer.
Louisiana
kevin@creativecontrolfilms.com
318.344.4308

Michele Coleman
Son Dylan has a critical congenital heart defect.
Lives in DC, baby was born and tested in Maryland.
coleman.michele@gmail.com
202.498.7757

Trish Cook
Daughter Maggie has isovaleric acidemia.
Texas
trishcook1@yahoo.com
469.774.7892

Teddi Miller
Son Evan has maple syrup urine disease.
New Mexico
grkteddibear@yahoo.com
229.251.4699

Honey Stecken
Daughter Maren has propionic acidemia.
Colorado
honeystecken@yahoo.com
719.588.3093

Beatte Weiss-Krull
Daughters Alena and Mia both have galactosemia.
Oregon
germanpdx@gmail.com
Office: 503.234.0355
Home: 503.236.6838

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• Check out APHL’s channel on Vimeo for content that can be shared on your lab’s website or via social media, for example: Happy 50th Birthday, Newborn Screening, 50 Years of Saving Babies’ Lives, One Family’s PKU Story, A Newborn Screening Success Story: The Best Moment in My Career, and an animated introduction to public health labs, What is a Public Health Laboratory? Other recommended content: My PKU Life (Kevin Alexander), Newborn Screening (Save Babies Through Screening Foundation), and Newborn Screening for Heart Defects (CCHD) Using Pulse Oximetry (Newborn Foundation, University of Minnesota Amplatz Children’s Hospital & Minnesota Department of Health).

Activities for “Day at the Public Health Lab” and Other Events

Everyone’s Birthday Party: Hold a birthday party for all the babies screened at the state lab over the last 50 years and their families and friends. Invite the families of children whose newborn screening conditions were detected by the lab to host the event.

• Print a custom “birth announcement” for each attendee with key stats about the newborn screening program, e.g., number of babies screened per year, number detected with conditions, etc.
• Stamp kids’ hands with “Made in (name of state).”
• Offer lab tours and/or demonstrations of aspects of newborn screening.
• Let kids try to drop spots of colored water onto filter paper.
• Team with local chapters of March of Dimes for displays, materials, volunteers and other ideas.
• Have kids bring baby dolls to have their picture taken with their baby.
• Serve birthday cake.

Credit to: Patricia Blake, Strategic Communications Director, State Hygienic Laboratory at the University of Iowa, 2012

Legislators Tour: Invite legislators to tour the lab and meet children and families whose lives have been touched by newborn screening. Share 50th Anniversary brochures and information about the achievements of your state’s newborn screening program.

School Tours: Invite senior high school and/or college science classes to tour the newborn screening laboratory in conjunction with their study of genetics and the human genome.

STEM Festivals: Participate in area STEM festivals to share newborn screening resources and information with families, educators and science professionals. Organize one or two interactive activities around newborn screening or related scientific concepts.

PREPARED TWEETS AND FACEBOOK POSTS

Copy these prepared posts to your health department’s Facebook page or Twitter feed for effortless publicity. If your department does not sponsor a Twitter feed, ask staff to tweet from their personal accounts.

Tweets:

► Happy 50th birthday #newbornscreening!
50 Years of Saving Babies’ Lives
bit.ly/APHL50

► Simple tests could save your newborn baby’s life. Learn more at bit.ly/APHL50 #newbornscreening

► Over 4 million screened – What is newbornscreening? bit.ly/APHL50

► Do you know your results? Important info for new and expectant parents bit.ly/APHL50 #newbornscreening saves lives

► Dear Mama and Dada, #newbornscreening could save my life. Know my results. Love, Baby bit.ly/APHL50

Facebook:

► What is one of the first things you can do to protect your baby’s health? Know your newborn screening results. Read more here and share with others: bit.ly/APHL50

► What is newborn screening? A simple test that could save your baby’s life. bit.ly/APHL50

► This simple test saves or improves over 12,000 lives every year in the U.S. Make sure you know your results. bit.ly/APHL50

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Resources for Interactive Activities

**How to Build a Human DNA Model—Out of Humans.** Group activity demonstrates that DNA is double-stranded and that strands are complementary and antiparallel. Zinnen, Tom, PhD, University of Wisconsin Biotechnology Center. (1992).

**DNA Program Kit: Fifty Years of DNA from Double Helix to Health.** Information and activities, including DNA extraction from wheat germ and DNA model building. National Human Genome Research Institute with U.S. Department of Energy, Science Museum of Minnesota and Association of Science and Technology Centers. (2003).

**Genetic Education Resources.** DNA Day Jeopardy, Genetic Mind Reader and other resources for tours and outreach. National Human Genome Research Institute.

**DNA Learning Center.** Excellent teaching materials, animated videos and other resources including Lab Center with online lessons; Gene Boy, a simple, multifunction DNA sequence analysis tool; and Your Genes Your Health, a multimedia introduction to genetic disorders. Cold Spring Harbor Laboratory.
CAMPAIGN MESSAGES

Key Messages

Newborn screening saves and improves the lives of more than 12,000 babies in the U.S. each year.

- Newborn screening is one of the largest and most successful public health and disease intervention initiatives in the country.¹
- More than 4 million newborns are screened annually in the U.S., protecting thousands of infants from disability and death.
- More than 6,000 babies each year are born with a genetic condition for which screening and treatment for the prevention of many or all of the complications of the condition are available.²
- About 6,000 babies each year are found to have hearing loss through newborn screening.
- Early detection by laboratory tests helps prevent death and disability from dozens of conditions.
- Early identification gives babies a healthy start and reduces healthcare costs associated with treatment of lifelong debilitating medical conditions.³

Newborn screening is a quick and safe way to help protect your child against certain diseases and medical conditions.

- Newborn screening begins within 24 to 48 hours of your child’s birth, soon after a few drops of blood that are obtained from a heel stick arrive at the lab. Health care providers follow up if further testing is needed.
- Although screening is automatic when your child is born, you should discuss the test ahead of time with your OB/GYN, pediatrician, nurse midwife or other healthcare professional.
- Newborn screening tests alert parents and healthcare providers to potential health issues. A child with a positive test result should have follow up tests right away.
- The Genetic Information Nondiscrimination Act is a Federal law that prohibits discrimination in health coverage and employment based on genetic information.⁴
- Clinical Laboratory Improvement Amendments (CLIA) regulations and the Health Insurance Portability and Accountability Act (HIPAA) ensure the confidentiality of protected health information.⁵

Newborn screening is one of the most sophisticated tools in the arsenal to protect public health.

- Fifty years ago, a simple heel prick and blood tests prevented newborns from developing phenylketonuria (PKU). Today, a few dried blood spots on the Guthrie filter paper card can reveal dozens of treatable medical conditions.
- The American College of Medical Genetics recommends screening for at least 31 conditions including medium-chain acyl-CoA dehydrogenase deficiency (MCADD), cystic fibrosis (CF), congenital hypothyroidism (CH), congenital adrenal hyperplasia (CAH), congenital deafness (HEAR) and critical congenital heart disease (CCHD).
- PHLs work closely with the Centers for Disease Control and Prevention, the World Health Organization and industry partners to ensure the latest in technology and procedures for screening millions of newborns each year.
- The American Academy of Pediatrics and American College of Obstetricians and Gynecologists recommend their members provide information and have discussions about newborn screening with their patients and parents.⁶⁷

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Undergirding Messages

Celebrating 50 years of state-mandated newborn screening, the Association of Public Health Laboratories defends the front lines of public health, protecting our country’s families and saving untold lives.

Public health laboratories are ever-vigilant, protecting our families’ health and saving lives every day.

• Every U.S. state and territory has a central public health laboratory that performs testing and other laboratory services, which may include outbreak detection, disease surveillance, newborn screening, clinical diagnostic testing, environmental and radiological testing, emergency response support, applied research, and laboratory training, to the communities they serve.

• Public health laboratories are responsible for screening more than 4 million babies in the U.S. each year, providing doctors and families with early, critical information to improve the lives of children with disease.

• The men and women of our public health laboratories are the first line of defense between the nation’s families and public health emergencies and outbreaks.

• Public health laboratories are entrusted with the most precious asset our country has to offer – our health and safety – and are the first to respond to public health emergencies.

• APHL acts as the central clearinghouse for knowledge sharing, advocacy and training for public health laboratories and their personnel.

5 U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Clinical Laboratory Improvement Amendments (CLIA) http://www.cdc.gov/clia/regs/toc.aspx
7 The American College of Obstetricians and Gynecologists, Committee on Genetics, Committee Opinion, Number 481, March 2011 (December 2007)
What’s Behind the Doors of a State Lab?
Join XXX Public Health Lab on (date) to Find Out

XXX—What goes on behind the doors of the laboratory that protects (state) residents from infectious diseases, foodborne illness, environmental hazards and potentially deadly or disabling congenital conditions? Find out on (date) when the (state) public health laboratory opens its doors to the public for a day of free family activities in celebration of the 50th anniversary of newborn screening.

Newborn screening is a vital public health service that saves or improves the lives of over 12,000 babies born in the United States each year, including (annual number detected) in (state). In 1963, the first state-mandated newborn screening programs began in Massachusetts, Oregon and Delaware. Fifty years later, over 4 million U.S. newborns are screened each year for certain genetic and metabolic conditions, hearing loss and critical congenital heart disease. For babies who test positive for one of these conditions, rapid identification and treatment can make the difference between health and disability, or even life and death.

At “Day at the Public Health Lab,” families and other members of the public can:

• Talk with scientists about how they monitor and detect diseases
• Try out the tools and concepts of lab science through interactive, family-oriented activities
• Tour lab facilities
• Celebrate the (annual number of births) babies born in (state) each year with (special activities related to newborn screening).

“This is going to be a fun event for visitors of all ages,” said (name and title of public health lab director). “You’d be amazed what goes on inside a public health lab. Lab scientists are detectives who track and identify pathogens and other health hazards. It’s exciting work, and we have great stories to share.”

“Day at the Public Health Lab” is organized in conjunction with a national public awareness campaign, Newborn Screening: 50 Years of Saving Babies’ Lives, co-sponsored by the Association of Public Health Laboratories (APHL) and the Centers for Disease Control and Prevention’s Newborn Screening and Molecular Biology Branch (NSMBB). To learn more about the campaign and related upcoming events, visit the campaign website or email newborn.screening@aphl.org. For more about newborn screening, see the campaign brochure and Find the Facts page.

Information concerning “Day at the Public Health Lab” is available at ... (name, phone, email, parking, etc.)

(Insert standard description of state health department.)