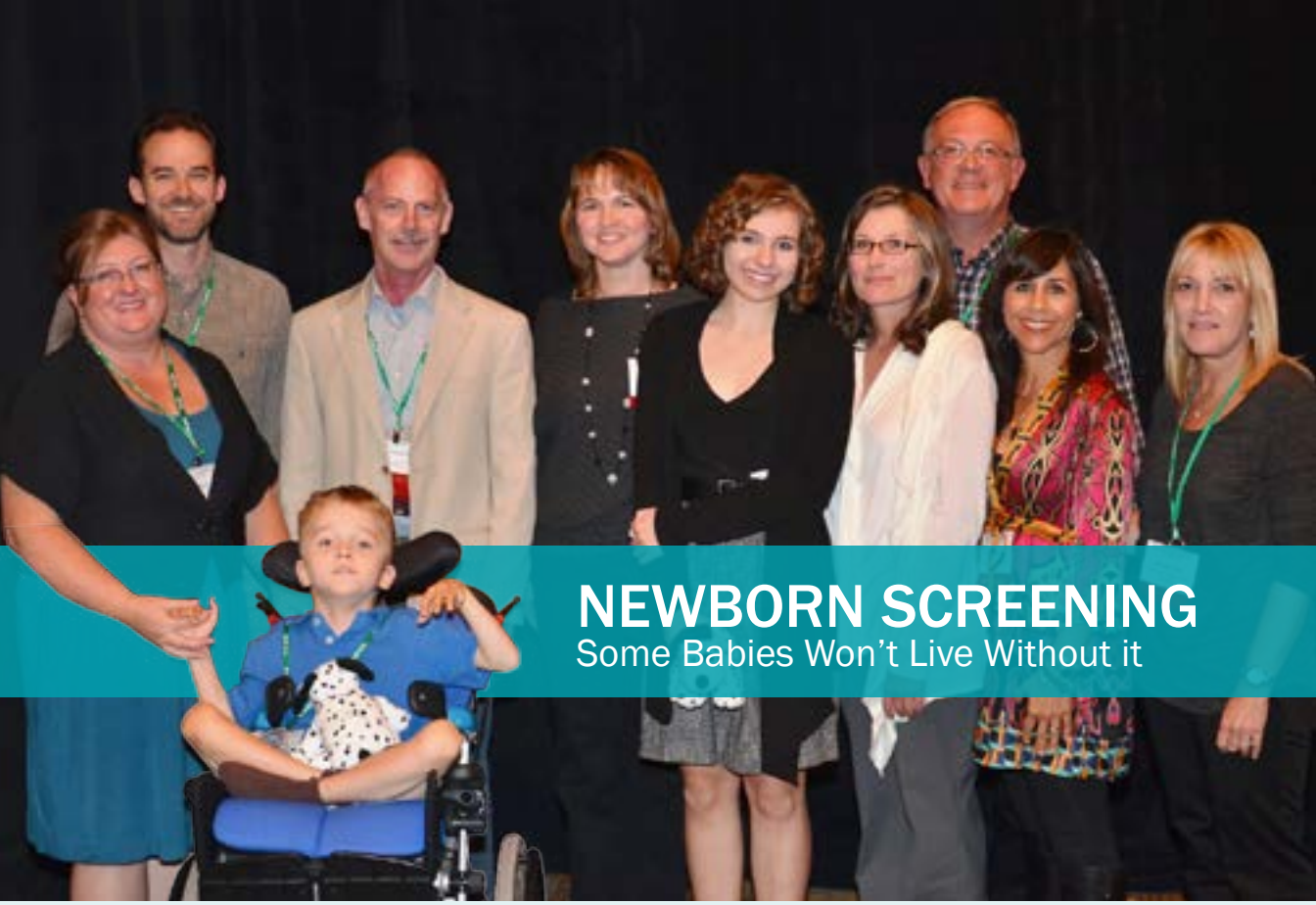
APHL ASSOCIATION OF PUBLIC HEALTH LABORATORIES

NEWBORN SCREENING

Four Facts Policymakers Need to Know



NEWBORN SCREENING

Some Babies Won't Live Without it

Zachary Wyvill APHL-CDC Newborn Screening and Genetic Testing Symposium parent/patient panel.

Two boys—Zachary Black and Zachary Wyvill—were born in Northern California one month and 60 miles apart. Zachary Black was tested for the rare genetic disorder glutaric acidemia Type 1 (GA1) in a pilot program run by the state public health laboratory to determine if the disorder should be added to California's routine newborn screening test panel.

He tested positive for GA1, which renders the body unable to digest most proteins in food. Zachary Black was immediately placed on a special, low-protein diet and is a happy, healthy child.

Zachary Wyvill also has GA1, but was not tested in the pilot study. It took physicians months (at considerable cost) to diagnose the disorder; long enough for toxic levels of undigested protein to accumulate in his body, causing severe neurological damage. Zachary Wyvill may never be able to walk, talk or even feed himself. His family's health insurance is nearly maxed out.

How important is newborn screening? **Ask the Wyvill family.**
What should policymakers know about newborn screening?
Read on.

FACT 1 NEWBORN SCREENING TOUCHES NEARLY EVERY BABY BORN IN THE UNITED STATES.

Anyone born in the United States in the late 1960s or later—including, perhaps, you or your children—almost certainly was pricked in the heel by a nurse or midwife, who collected a few drops of blood to send to a laboratory for newborn screening. Trained scientists tested the blood for potentially devastating heritable and congenital conditions (i.e., conditions present at birth) that are treatable, but difficult or impossible to detect without deliberate testing.

In addition to blood-based testing, between about 2000 and 2003, today all states offer newborn hearing screening to all or select newborn populations.[i] Pre-discharge screening for critical congenital heart disease—the latest disorder recommended for newborn screening—has recently begun.

Hopefully, no one in your family has been diagnosed with a condition detectable by newborn screening. Yet, each year, more than 12,000 US babies are.[ii] Without the early interventions enabled by newborn screening, many of these youngsters would suffer lifelong disabilities or early death. And their families would be forced to undergo costly diagnostic odysseys to figure out why their babies are failing to thrive … or why they died so tragically young.

Virtually all (>98%) of the roughly 4 million babies born in the US each year receive newborn screening.[iii] And virtually all newborn screening is done under the authority of state governments and is automatic unless parents opt out in accordance with state laws.[1] The vast majority of screening tests are performed in a state public health laboratory or in a partner laboratory under state public health laboratory oversight.[2]

> "No child should die or suffer disabilities if a simple blood spot can prevent it."
>
> **Robert Guthrie, PhD, MD, 1916-1995**
> Developer of the first newborn screening test
> (the Guthrie test for PKU)

1 Physicians or parents can also order newborn screening tests directly from private laboratories, but this testing accounts for only a minute portion of all newborn screening.

2 Only Nebraska, Mississippi and Washington, DC, contract directly with a commercial laboratory for newborn screening services, without state public health laboratory oversight. These jurisdictions account for about 3% of US births. In addition, hearing and heart screening are performed at birthing facilities and are usually not associated with laboratory testing.

FACT 2

NEWBORN SCREENING IS A PUBLIC HEALTH SUCCESS STORY.

Newborn screening has been called "a triumph of the 20th century public health system."[iv] More recent newborn screening innovations are considered among the greatest public health achievements of the early 21st century.[v]

In short, newborn screening has been a spectacular success because it saves lives, prevents disability and saves money.

Untreated infants with newborn screening conditions, and their families, may suffer enormous burdens. Untreated infants with PKU, for example, will have an average IQ below 40, a severe intellectual deficiency. Untreated infants with MCADD may suffer sudden death. And untreated infants with biotinidase deficiency may have unstoppable seizures, hearing loss, blindness and movement difficulties. Yet, babies with these disorders often appear healthy at birth.

Perhaps the most painful burden for families whose children suffer the consequences of untreated early disease is knowing that adverse outcomes could have been prevented. For PKU, the main treatment is a low-protein diet. For MCADD—regular feeding. And for biotinidase deficiency—supplements of the vitamin biotin.

By enabling prompt treatment, newborn screening keeps rare congenital conditions from stealing children's lives.

Table 1. Most Common Newborn Screening Disorders in the United States

Disorder	Estimated # of US Cases Annually*	Main Problem	Potential Outcome Without Timely Intervention	Main Treatment
Hearing loss	5,073	Inner ear malformation or injury due to birth defects, genetic disorders, exposure to infections or toxicants in the womb	Delayed language acquisition, decreased psychosocial well-being, behavior problems, lower educational attainment	Surgery, medications, ear tubes, speech therapy, cochlear implant or sign language instruction, depending on cause
Primary congenital hypothyroidism	2,156	Insufficient thyroid hormone	Severe, permanent intellectual disability	Thyroid hormone supplementation
Sickle cell disease (Including sickle cell anemia, sickle C disease, hemoglobin S/β thalassemia)	1,775	Defective red blood cells carry less oxygen to the body and clog blood vessels	Delayed growth and puberty; episodes of severe musculoskeletal pain; leg ulcers; jaundice; possible blindness in older children and adults; possible organ damage	Folic acid supplementation, high fluid intake, monitoring for complications. [Thalassemia was once universally fatal. With early treatment, it is considered a chronic illness.]
Cystic fibrosis (including non-classical)	1,248	Inherited defect in the glands that secrete mucus and sweat	Lung and digestive problems (as excess mucus blocks airways and pancreatic ducts); early death from respiratory failure	Chest physical therapy, medications to thin mucus and dilate airways, oral pancreatic enzymes, vitamin supplements. [Treatment can prolong life into the 50s or longer.]
MCADD (Medium-chain acyl-CoA dehydrogenase deficiency)	239	Inability to use fat for energy	Sudden death	Keeping baby from fasting longer than overnight
Classical galactosemia, plus variant	224	Inability to metabolize the milk sugar galactose	Liver failure, brain damage	Galactose-restricted diet
PKU (Phenylketonuria) and clinically significant variants	215	Inability to metabolize phenylalanine, an amino acid in most protein	Severe, permanent intellectual disability; seizures; stunted growth	Low-protein diet
Congenital adrenal hyperplasia (excluding non 21 hydroxylase deficiency)	202	Abnormal production of adrenal gland hormones (typically insufficient cortisol and excess androgen)	Problems range from mild to severe, possibly including shorter height than parents, early signs of puberty, low blood pressure, low blood sugar, altered development of external genitalia, infertility	Hormone replacement therapy

* Based on number of infants diagnosed with hearing loss in 2009 per CDC Early Hearing Detection and Intervention Program annual data (available at http://www.cdc.gov/ncbddd/hearingloss/ehdi-data2009.html) and incidence of other conditions in four state newborn screening programs (CA, MA, NC, WI) during 2001–2006 (reported in MMWR 2008;57:1012-5). *Source: CDC. CDC grand rounds. Newborn screening and improved outcomes.* MMWR 2012;61(21);390-393.

"Economic benefits from early detection of congenital hypothyroidism alone more than cover the cost of the entire newborn screening infrastructure."

Scott Grosse, PhD
Research Economist
National Center on Birth Defects & Developmental Disabilities, Centers for Disease Control and Prevention

Over and over again, studies have found that newborn screening not only transforms lives, but also saves money. Here are three compelling examples.

- The Medicaid cost of treating a baby with SCID—a severe immunodeficiency that is uniformly fatal in the first two years of life without immune reconstitution—can easily top $2 million.[vi] Yet, if infants are diagnosed early, before developing life-threatening infections from exposure to live childhood vaccines or common germs, they can be cured with a bone marrow transplant. The cost of the transplant? Just $100,000 if performed within the first 3.5 months of life.[vii]
- Nationwide newborn screening for congenital hypothyroidism, which occurs in about 1 in 2,000 US births, saves an estimated $400 million/year or more by preventing the IQ loss that may occur without early (and inexpensive) thyroid hormone supplementation.[viii,3] This savings is 20 times the cost of laboratory screening for congenital hypothyroidism.[ix,x]
- The benefits of tandem mass spectrometry (MS/MS) screening of 540,000 California newborns for a panel of more than 40 conditions exceeds annual program costs by $47.1 million.[xi] Or, stated another way, every dollar California spends on MS/MS screening yields a benefit of $9.32, including medical costs avoided and the value of lives saved.

3 The $400 million/year savings includes the sum of benefits of preventing disability (e.g., averting the need for special education and other services) and the increased productivity gained by averting mild IQ losses among those in the normal range of IQ scores.

WHEN 1 IS THE BIGGEST NUMBER

Everett's Story

Korissa Olson is a model mom. She feeds her family organic food, exercises every day and performs in a professional gospel singing group.

Her son, Everett, was born April 14, 2008, in Minneapolis' North Memorial Hospital. It was, said Korissa, "a great pregnancy" and "a perfect textbook delivery," with no drugs, no complications.

"I felt great, and Everett was beautiful," she said.

But when a nurse asked Korissa about newborn screening, she said, no.

Someone had handed her a flier after church one day, discouraging the practice. "I'm an educated person," said Korissa. "I was reading up on vaccines, on food for newborns, on caring for a newborn. But you don't think about newborn screening when you're pregnant. I just filed [the information] in the back of my head. I really didn't have time to research it, and there are no known genetic disorders in my family."

But the nurse came back a second time. And then a third. "She gave me a brochure," said Korissa, "and I read it, and I realized that this is not an invasive test. They're not putting anything into my baby's body, they're just taking out a few drops of blood." She said, "I have a strong belief in God, and I just knew right then and there that I was gonna have this test."

Soon afterward, Korissa and her husband took Everett home, a seemingly healthy baby boy. But at his first health check-up four days later, Korissa said, "My pediatrician sat me down right away and showed me this paper from the Minnesota Department of Health with the word *galactosemia* on it. She told me Everett had tested positive for this disorder."

The pediatrician advised further testing to confirm the result. In the meantime, she said, Korissa should stop breastfeeding, since babies with galactosemia lack the enzymes needed to digest the milk sugar galactose.

"I felt very strongly about breastfeeding," said Korissa, "so it was really, really hard. Then I read *cataracts, brain damage, liver failure, learning disabilities.* I was overwhelmed. I thought surely it was a false positive; he looked so healthy."

Korissa went home and did her own research. "I realized how serious it was," she said, "so I did stop breastfeeding." The very same day, Everett got sick.

"He became instantly lethargic, his eyes rolled to the back of his head. I called the pediatrician and said, 'I just can't wake him up.'"

Everett was admitted to the neonatal intensive care unit with severe jaundice, a problem routinely treated by giving babies fluids, including breast milk. But because Everett was suspected of having galactosemia, doctors knew breast milk could be fatal.

The newborn screening result, said Korissa, "saved our little Everett's life."

Everett was discharged three days later; and two weeks later, Korissa and her husband received confirmation that their son had the most severe form of galactosemia.

"It was hard at first," said Korissa, "but I think we were very, very blessed. Untreated galactosemia has a 75% mortality rate, but we had an early diagnosis. I've actually called the nurses back and thanked them over and over again [for encouraging newborn screening]."

Everett, for his part, is now a "sparkly" four-year-old who loves people and loves to play. He has, said his mom, become a "spokestot" for newborn screening, appearing in *Parents* magazine, on the cover of *Minnesota Medicine* and with Korissa at legislative hearings. Other than minor speech problems and a galactose-restricted diet, he looks and acts "very normal."

Said Korissa, "Galactosemia only affects about one in 60,000 babies. You think, *that's not going to happen to me.* But when your baby is the one, one is the biggest number."

She said, "I wake up most mornings thankful that Everett had that test. My life—and Everett's life—would have been so very different without it." ▪

In 2008, the Minnesota Public Health Laboratory Division screened 71,636 infants. Eight were diagnosed with some form of galactosemia, including Everett.

FACT 3 NEWBORN SCREENING IS MORE THAN A TEST.

Public health laboratory testing is a critical, core component of newborn screening. Yet, laboratory testing—and pre-discharge hearing and heart screening—are just one piece of a broader public health system working for families.

Every state newborn screening program has six essential parts.[xii]

1. **Screening:** Collection of newborn blood specimens and testing to identify infants with potential markers of congenital conditions (e.g., elevated or depressed levels of certain body chemicals) and point-of-care hearing and heart screening. Each state decides what conditions to include in its newborn screening test panel.
2. **Follow-up:** Rapid location and referral of screen-positive infants; that is, infants with test results outside a specified range.
3. **Diagnosis:** Medical evaluation and additional testing of screen-positive infants to make a definitive diagnosis or determine that the screening result was a false-positive.
4. **Management:** Rapid planning and implementation of long-term therapy for infants diagnosed with a newborn screening disorder.
5. **Evaluation:** Assessment of the previous four activities to identify opportunities for quality improvement and gauge benefits to the patient, family and society.
6. **Education**: Education of the parents, primary care provider, legislators, newborn screening personnel (lab and follow-up) and stakeholders.

In addition, the federal government supports state newborn screening programs in several important ways.

The **Centers for Disease Control and Prevention** (CDC) is the only comprehensive source of quality assurance materials for dried blood spot testing in the United States and the world. It assures the quality of the special filter paper used to collect infant blood spots; runs a voluntary program (operated jointly with the Association of Public Health Laboratories) through which newborn screening laboratories can evaluate their testing proficiency; and offers screening laboratories testing guidelines, trouble-shooting assistance and the reference materials needed to calibrate testing instruments and carry out other quality control activities. The agency also conducts and funds newborn screening research, evaluations and pilot studies, and, with the Association of Public Health Laboratories, is helping newborn screening laboratories plan for continuation of vital testing services during large-scale natural disasters and other emergencies.

The **US Health Resources and Services Administration** (HRSA) was instrumental in the development of the *uniform newborn screening test panel* recommended for all states. Since passage of the Newborn Screening Saves Lives Act of 2008,[xiii] the agency has had a renewed mandate to strengthen the newborn screening infrastructure. It funds several activities to enhance states' genetics and newborn screening services and to improve newborn screening education, coordinated follow-up care and long-term surveillance to document outcomes and enable researchers to assess the benefits of screening.

Ultimately, as shown in Table 2, newborn screening depends on a host of partners, working together at every level of society.

Table 2. Newborn Screening Partners and Their Roles

Newborn Screening Partner	Role
Federal and state legislators	Assure adequate funding and legal authority to maintain the newborn screening infrastructure and carry out newborn screening activities
Maternal and pediatric healthcare providers	Educate parents about newborn screening before childbirth and, if necessary, inform them of out-of-range screening results
Families	Make informed decisions about newborn screening and provide input to improve the newborn screening system
Scientists in public health laboratories and partner screening laboratories (In most states that contract with a commercial laboratory for newborn screening, the state public health laboratory is ultimately responsible for the quality of testing.)	Choose appropriate test methods, validate and implement new screening technologies, assure high-quality testing that detects infants with congenital conditions while minimizing false positive results, communicate screening results to follow-up personnel, and translate advances in genetics and genomics into new screening protocols (either improved testing strategies to replace those now in use or tests for conditions under consideration for addition to the state testing panel)
State newborn screening program administrators	Assure that all infants with out-of-range screening results receive diagnostic testing and immediate follow-up care, if needed; provide policy guidance; provide education/outreach to families, healthcare providers and others
Medical specialists	Diagnose infants with newborn screening conditions and co-manage their care with primary care providers
State maternal and child health programs	Link families with high-quality medical management and care coordination after newborn screening conditions are diagnosed; track clinical outcomes
Federal Agencies (CDC, HRSA)	Provide technical assistance and guidance to state newborn screening programs; collect and analyze newborn screening data; assure availability of comprehensive consumer and professional resources
Professional associations (e.g., Association of Public Health Laboratories, American College of Medical Genetics and Genomics)	Educate the public and professionals about newborn screening; promote the development and diffusion of newborn screening innovations; act as liaisons between professionals and key partners
Family advocates and advocacy groups (e.g., Save Babies Through Screening Foundation)	Raise awareness of newborn screening; assist families; advocate for improvements in the newborn screening system
Research funders (e.g., National Institutes of Health) and researchers at federal agencies, public health laboratories, universities, newborn screening test kit manufacturers, private research institutes	Assure continual improvements in newborn screening technology and practices

THANKS TO NEWBORN SCREENING, JAZMIN CAN DANCE

Adaly Sanchez and her husband Victor were thrilled to welcome their first child in 2010, a beautiful baby girl named Jazmin.

Jazmin, said Adaly, was born in Silverton, Oregon, one day after her due date: "I went to the hospital early in the morning because I started with the pain. They sent me home. Then I went back in the evening. I didn't have ten minutes at the hospital and she was out already."

A skinny and purplish newborn with peach fuzz hair, Jazmin weighed 5 pounds and 12 ounces. She and Adaly went home two days later. But soon thereafter, Adaly received a call from her pediatrician with life-changing news: Jazmin had tested positive for analytes associated with methylmalonic acidemia (MMA), an inherited disorder that renders the body unable to process certain proteins and fats. Without treatment, MMA would likely cause intellectual disability, kidney disease, pancreatitis, coma or even death.

Adaly took Jazmin back to her pediatric clinic, where providers asked a lot of questions. "They touched her skin and weighed her and asked how she was eating, pooping, peeing, sleeping," said Adaly. The answers were not out of the ordinary; Jazmin had been doing well. "She didn't get sick right away," said her mamá. "She took a little bit [of] time."

Jazmin was immediately referred to the Child Development and Rehabilitation Center at Oregon Health & Science University (OHSU), where specialists could provide advanced care. At OHSU, the first-time parents met with a physician who examined Jazmin and initiated follow-up tests that confirmed the newborn screening result. They also met with a nutritionist, who explained that Jazmin would need to follow a special low-protein diet to stay healthy. Healthcare providers explained that MMA is a recessive disorder, meaning that a defective gene must be passed onto the baby from each parent.

"We didn't know [we were

carriers]," said Adaly. "I didn't know exactly what was MMA. It was a big surprise for us; she was our first baby. I was scared. They told me she was going to take longer to learn things, to walk, to talk."

In fact, however, Jazmin has exceeded all expectations. She began crawling and talking at nine months and started walking at one year. "She has been doing good," said Adaly, who gives Jazmin prescribed dietary supplements and regularly calls providers at OHSU to verify that new food items are okay for her daughter to eat.

Today, Adaly said, Jazmin has a lot of hair and "likes a lot to dance."

When Jazmin was just a few months old, Adaly found out she was pregnant again, and worried about the 25% chance her second child might have MMA too. The Oregon State Public Health Laboratory—which performs newborn screening for all Oregon babies—expedited the test results, which were 100% normal.

At the moment, Jazmin is not entirely happy with her new sister. "She doesn't like when her dad carries the new baby, and she cries and cries and cries," said Adaly.

With regard to newborn screening, Adaly said, "I think it is really good. If I didn't have that, I wouldn't know Jazmin was sick. I think I would have given her things [to eat] that would have made her really, really sick." She said, "I hope they never stop doing that, because that is actually a lot helpful. I think it did save her life."

The Oregon State Public Health Laboratory, which administers the Northwest Regional Newborn Screening Program, screens about 167,000 babies each year, including about 45,500 babies born in Oregon and 121,500 babies born in five other states. ▪

In 2010, 375 infants screened by the Oregon State Public Health Laboratory were diagnosed with a condition initially detected through newborn screening. Six babies, including Jazmin, were diagnosed with MMA.

FACT 4 NEWBORN SCREENING IS A DYNAMIC PROGRAM—EVOLVING, IMPROVING

The US newborn screening system has been protecting infants for more than 50 years, ever since the development of the first screening test and the dried blood spot collection system that is still in use today. That first test, the Guthrie test for PKU, was widely implemented in the 1960s. Many states added a test for congenital hypothyroidism in the 1970s, and, by the 1990s, some states were screening for as many as nine or ten conditions (counting sickle cell variants as one disorder).

Tandem mass spectrometry has revolutionized the field, beginning in the late 1990s, and now enabling testing for more than 40 metabolic conditions with just one assay and one dried blood spot.

In 2006, the Secretary of the US Department of Health and Human Services approved a *uniform newborn screening panel,* listing tests recommended for all state programs. The new federal guidance spurred the adoption of tandem mass spectrometry across the country. In 2002, some states were screening for just four conditions, while others were screening for up to 36; by April 2011, all states reported screening for at least 26 conditions on the recommended uniform screening panel.[xiv,xv]

This widespread newborn screening expansion has led to earlier life-saving treatment and intervention for at least 3,400 additional newborns each year with selected genetic and endocrine conditions.[xvi, xvii]

Today, the newborn screening system continues to evolve, with many challenging opportunities ahead.

The initial recommended uniform screening panel contained 29 core conditions.[xviii] It has since grown to 31, with the addition of SCID in 2010 and critical congenital heart disease in 2011.[xix] As advancing technologies allow for the detection of markers for more conditions, and advocacy increases, there will be continued pressure for state newborn screening programs to expand their panel of screening disorders.[4]

4 Anyone may nominate a condition for consideration for inclusion in the recommended uniform screening panel. All nominated conditions are reviewed by the US Department of Health and Human Services (DHHS), Secretary's Advisory Committee on Heritable conditions in Newborns and Children, following a rigorous, evidence-based process. Final decisions are made by the DHHS secretary.

Most states charge fees for screening—ranging from about $14.00 to $140.00 in 2007.[xx] But because fees rarely cover program costs, they are often supplemented with other state or federal funds. As these other resources decline, it becomes more difficult to support existing newborn screening activities, much less new initiatives.

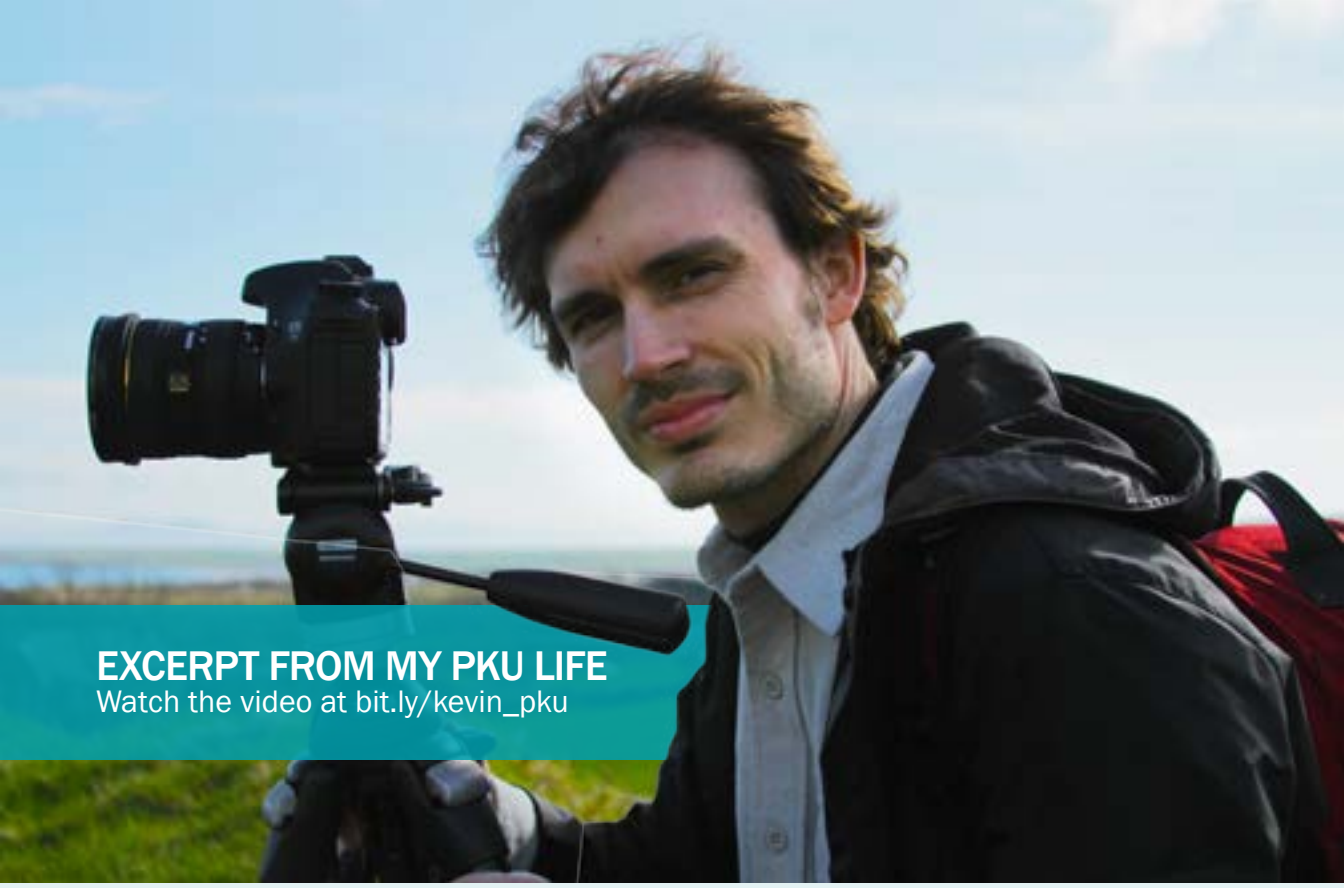
In addition to expanded blood-based testing, state newborn screening programs face a number of other challenges:

- Integrating point-of-care tests (e.g., pulse oximetry for screening of critical congenital heart disease) into NBS programs.
- Addressing genomics challenges, such as the interpretation of DNA test results.
- Developing policies and an infrastructure to facilitate the use of leftover newborn screening blood specimens—so-called *residual dried blood spots*—for valuable public health research.
- Addressing serious shortages of medical experts qualified to manage the care of infants with rare newborn screening conditions.
- Addressing the lack of public understanding of newborn screening.
- Improving and standardizing long-term follow-up activities to ensure the best possible outcomes for individuals. For example, there is a need for smoother transitions from pediatric to adult care and also a need for uniform data standards to track clinical outcomes and improve the quality of care.

Public Health Laboratories: Advancing Newborn Screening Through Technological Innovation

Public health laboratories are continually improving newborn screening services and looking for ways to contain costs. They are:

- Expanding the use of automation;
- Assessing, with partners, the feasibility and benefits of adding select conditions to state newborn screening test panels;
- Expanding DNA testing;
- Reducing the rate of false positive test results through the use of tiered testing strategies using both biochemical and molecular assays;
- Examining the use of single tests to detect multiple newborn screening conditions.



EXCERPT FROM MY PKU LIFE

Watch the video at bit.ly/kevin_pku

My name is Kevin Alexander. I'm 31 years old, and I have PKU. PKU is a very rare genetic disorder in which the body cannot properly break down protein. I've had this my entire life. It's become my normal…I've never had a steak, I don't eat chicken, bacon. I don't eat cheese, I don't drink milk. This is my normal, this is my life. It's all I've ever known. But, I've had a really good life.

I've spent the last ten years in professional video production. I've been a news videographer, a corporate videographer, a wedding videographer.…I covered Hurricane Katrina; I was down in New Orleans just five days after the storm. I have interviewed numerous celebrities. I've interviewed senators. I've interviewed governors… I've traveled the world shooting videos; I've traveled the world doing what I love to do.

Everything I love about life has been dependent upon my diagnosis with PKU—the fact that it was caught. I didn't choose to have PKU. I didn't choose the family I was born into, I didn't choose the country that I was born into, I didn't choose the time that I was born. But all of those factors just aligned at the right time for me to have a productive and healthy life. Had I been born 30 years [earlier], had I been born into a different family, had I been born in a different country…had I not been diagnosed, had I not always been on diet, had I not always been on my [medical] formula, it is undeniable that I would have been in an institution, that I would have become mentally retarded. When I think about the fact that my life could have been so different, it's a wake-up call to be thankful, honestly. But I've had a really good life…40 or 50 years ago, I would not have been able to do any of this.

We have some challenges today in our PKU community. Please know that the quality of life for everyone with this disease depends upon the decisions being made today.

I'm just asking on behalf of 20,000 [Americans living with PKU] who don't have a very powerful voice right now, please become educated on this issue. Please do whatever you can to help us, because we would greatly, greatly appreciate it. ▪

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More Information:

Newborn Screening Program, Association of Public Health Laboratories | http://bit.ly/PByUYu

Newborn Screening, Centers for Disease Control and Prevention | http://1.usa.gov/NyCCp9

Baby's First Test, facts about newborn screening | http://bit.ly/Ugnvz1

One Foot at a Time, video explaining newborn screening process | http://bit.ly/PBzzt8

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