

### **New Jersey Prioritizes Newborn Screening Program in the Face of Hurricane Sandy**

*Superstorm Sandy made landfall on the East Coast on Oct. 29, 2012, causing billions in damage and killing 159 people, making it one of the worst natural disasters the country has ever seen.*

The most sizable storm to hit New Jersey in more than 100 years, Sandy caused unprecedented damage across the state: 346,000 homes and housing units were damaged or destroyed, more than 2.7 million households and businesses were without power, nearly 600 full or partial road closures occurred, and, at the height of the sheltering effort, an estimated 7,005 residents were housed in shelters.

In spite of the destruction, New Jersey's only designated newborn screening lab teamed up with state and local partners, as well as other stakeholder groups, to ensure that not a single newborn screen was missed in the days after the storm. The newborn screening lab is housed within the New Jersey Department of Health (NJDOH), which is led by Commissioner Mary E. O'Dowd. Scott Shone is the manager of the newborn screening lab program.

CDC calls newborn screening (NBS) systems one of the greatest public health achievements of the 20<sup>th</sup> century. In New Jersey the NBS process begins shortly after birth—usually within 24 to 48 hours, while the baby is still in the hospital—and involves a hearing test, pulse oximetry screening, and heel stick to retrieve a few spots of blood that are dried on a piece of filter paper. Every day, hospitals send the filter cards collected from newborns to the state-designated laboratory for screening.

It is crucial to screen newborns shortly after birth because some metabolic conditions can cause intellectual and physical disabilities or kill infants within days, even when they otherwise appear healthy. Many children with diseases covered by NBS can live healthy, normal lives if their conditions are caught and treated within their first days of life. In New Jersey, the specimens are screened almost immediately for 54 genetic and metabolic conditions. The lab mails normal results to the hospital of birth and a follow-up team contacts the infants' healthcare providers with abnormal results. Ideally, parents go over all test results—even normal ones—with their pediatrician during the baby's well checks. Nationally, NBS saves and improves the lives of more than 12,000 at-risk babies each year.

New Jersey's Newborn Screening Program lab tests samples from more than 100,000 babies born in the state each year. About one infant in every 368 is identified with one of the disorders for which the state screens. During Superstorm Sandy, under the leadership of Gov. Chris Christie and NJDOH, NBS program staff, UPS, the state hospital association, and other state leaders worked tirelessly to ensure that the storm did not interrupt the time-sensitive screening process. During the storm and the days immediately following, the NBS lab screened more than 1,000 specimens. The state's success at keeping NBS going

- New Jersey's NBS lab processes more than 120,000 specimens a year. They didn't miss a single one during the storm.
- The NBS lab was the only location in Central New Jersey to receive a UPS delivery on Oct. 29, just before the storm hit.
- Staff processed more than 1,000 specimens Oct. 29-31.

without interruption became a “how to” example for public health leaders crafting their own emergency preparedness plans.

### Steps Taken:

- The state of New Jersey, as part of routine emergency preparedness, had already developed plans and trained personnel to respond to major natural disasters such as hurricanes. The preparations mentioned below are intended only to highlight the role of the NBS lab in emergency preparedness. New Jersey’s statewide emergency preparedness plans are available the Office of Emergency Management’s [website](#).
- The NBS lab is located within the New Jersey Department of Health (NJDOH)’s Division of Public Health Infrastructure, Laboratories, and Emergency Preparedness, giving it an organizational tie to statewide emergency preparedness and response.
- NBS hosted tours for a variety of state and federal programs with emergency response and preparedness responsibilities to ensure it had effectively communicated the program’s vital public health role.
- The lab itself had an emergency preparedness plan in place, which they developed in collaboration with other state labs after Hurricane Katrina destroyed Louisiana’s NBS lab.
- The HRSA-funded regional collaborative, which New Jersey belongs, New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC), brought together NBS labs and other stakeholders to develop contingency plans. These covered short- and long-term issues, such as how a lab might bring in additional staff to cover an indefinitely increased workload or how technology might allow labs to assist each other from a distance. Emergency preparedness planning was one of the many issues the Consortium works on. The Consortium describes their overall goal as “ensuring that individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home.”
- New Jersey’s lab has built-in efficiencies that allow the scientists to get things done accurately and quickly. As the storm approached, lab staff worked to clear the weekend’s specimens, leaving nothing for the next day, because they were not sure what damage the storm might bring overnight.
- On a normal day, the lab relies on UPS to collect samples from the state’s 56 birthing hospitals and deliver them to the NBS lab by 10:30 a.m. the next day. The NBS lab was assigned a new UPS account representative less than a month before the hurricane. Lab staff gave her a tour of the lab and provided in-depth education on NBS’s role in public health. The account representative became a willing, effective advocate when the lab needed UPS during the storm because she understood the delicate timing of NBS.
- The UPS representative successfully advocated within her organization to make Monday’s specimen delivery to the lab, even though UPS had suspended delivery service in the face of Sandy’s landfall. Shone calls UPS a “phenomenal partner that really worked with us through a variety of issues.”

### Results:

- After Sandy made landfall on Monday evening, UPS was shut down and state systems were interrupted and severely compromised. Shone worked with other state officials into Monday evening—with the storm raging—making ad hoc plans to keep the NBS lab up and running.
- The New Jersey Hospital Association (NJHA) facilitated some of these communications and acted as a proactive partner throughout the natural disaster. NJHA was a logical partner because they had the infrastructure in place to communicate with all of the state’s hospitals.
- Medical coordinating centers (MCCs) were activated during Sandy. MCCs are regional centers for public health operations that are essential for public health function coordination during disasters or other emergencies. MCCs are designated in state preparedness plans and staff at designated MCCs are trained on their roles in a disaster.
- Immediately after Sandy hit, hospitals decided not to rely on UPS delivery to get the samples to the NBS lab, but instead coordinated among themselves to get specimens to the MCCs.
- State officials authorized the use of state police to retrieve the samples at MCCs and deliver them to the lab on Tuesday and Wednesday.
- Shone and others are now working to formalize these procedures before the next emergency occurs.

### Lessons Learned:

- Learn from other states’ experiences. New Jersey created a preparedness plan for NBS after Hurricane Katrina destroyed Louisiana’s NBS lab, alerting NJDOH staff to the importance of pre-crisis planning.
- Work together and educate stakeholders before an emergency strikes. “Peacetime” efforts to educate public health leaders, policymakers, and other partners on the importance of NBS and the delicate timing of the process at the NBS lab were critical. Because NJDOH had communicated the importance of screenings before Sandy struck, state leaders understood the value of NBS screening and why it needed to continue through the disaster. Without educated partners, the state could have had a

### Timeline: In the New Jersey NBS Screening Program Manager’s Words

**Monday:** With the storm approaching and all state offices closed, UPS suspended service. However, 19 of our 34 NBS lab staff members still made it into the office and our local UPS center made the day’s delivery. I sent most of my staff home by 2 p.m., but a few of us stayed until 4 p.m., which was about three hours before Hurricane Sandy made landfall. The drive home was wicked, to say the least.

**Tuesday:** The state remained closed and most staff stayed home. State troopers delivered 412 specimens from 21 hospitals and a skeleton crew of six handled the testing. Many of the follow-up staff worked from home without power.

**Wednesday:** State offices were still closed, but nearly all staff made it in. State troopers delivered 576 specimens from 40 hospitals. The lab’s mail was backing up because the Capitol Post Office was still closed, so staff paid out-of-pocket to mail more than 500 envelopes at a local post office.

**Thursday:** The state officially reopened, and by then, UPS had restored specimen pickup services.

--**Scott Shone**, edited from the *CDC Works for You 24/7 Blog*

Source: <http://blogs.cdc.gov/cdcworksforyou24-7/2012/11/nj-newborn-screening-lab-perseveres-through-hurricane-sandy-keeps-hundreds-of-babies-safe/>

disorganized backlog of specimens, and the decision to use MCCs and state troopers may have been delayed receiving needed treatments.

- Effective communication and leadership at the top levels of government and public health make a difference in outcomes. Shone hails NBS's "phenomenal partners, who all understood the critical nature of what we do and their role in the process."
- "Emergency preparedness isn't just about the work that must get done, but the people who have to do the work, sometimes in the face of their own personal loss or difficulty," says Shone. NBS staff made heroic efforts to keep the program going, in spite of damage to their own homes, lack of electricity, and extreme transportation challenges.
- "You cannot plan for everything, so know that you'll have to react to what goes wrong," says Shone. "Be flexible and clearly communicate your needs."

**For more information:**

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