



PREPAREDNESS FOR PEDIATRIC PRACTICES NEWBORN SCREENING IN EMERGENCIES

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™



States have newborn screening programs and systems in place to ensure that newborns are screened and treated for preventable complications from certain congenital disorders. These programs are designed to assist the primary care pediatrician and specialists in carrying out confirmatory processes and connecting families to needed services. It is important to note that an “abnormal” result on the newborn screening panel (eg, out-of-range dried blood spot result, non-pass point-of-care result) is not a confirmed diagnosis. Prompt action is needed to confirm the diagnosis and initiate timely intervention because some congenital conditions can be rapidly disabling and even fatal. Early diagnosis and treatment of certain conditions can make a significant difference in improving health outcomes for affected children.

Because the individual conditions detected by newborn screening are rare and screening is designed to detect asymptomatic individuals, primary care pediatricians are *unlikely* to recognize these conditions before symptoms arise if screening does not occur. It is important that pediatricians ensure processes are in place for documenting that newborn screening was done and communicating results to the family.

A missed out-of-range dried blood spot or point-of-care screen can have devastating consequences for an affected child and family. Maintaining newborn screening systems on a daily basis is important, and contingency planning in an emergency or a disaster is crucial. Pediatricians, pediatric care professionals, and office staff should be involved in the process of disaster planning for the office. Existing office preparedness plans should be expanded to include contingency planning for interruptions in the newborn screening process.

CONTINGENCY PLANNING

The US Congress recognized the potential public health disaster that disruption of the newborn screening system would cause when it passed the Newborn Screening Saves Lives Act of 2007. In this legislation, Congress asked the Centers for Disease Control and Prevention to collaborate with the US Health Resources and Services Administration and state public health departments to develop a national contingency plan for newborn screening for use by a state, region, or consortia of states in the event of a public health emergency. A panel of experts was convened to develop the Newborn Screening Contingency Plan, which identifies planning, preparedness, and response activities around the following 8 strategic objectives:

1. The collection and transport of specimens
2. The shipment of specimens to state newborn screening laboratories
3. The processing of specimens

4. The reporting of screening results to physicians and families
5. Diagnostic confirmation of positive screening results
6. Ensuring the availability of treatment and management resources
7. Educating families about newborn screening
8. Other activities recommended by the US Department of Health and Human Services

Although pediatricians and others who care for children may not yet be involved in state preparedness planning, they should be aware that each state has points of contact for newborn screening and contingency planning.

NEWBORN SCREENING—PEDIATRICIANS CAN MAKE A DIFFERENCE

Newborn screening includes screening tests, short-term follow-up, diagnosis, treatment, long-term management, evaluation, and education activities. Program efficiency and effectiveness depend on the smooth integration of birthing center, laboratory testing, state reporting, and primary care systems.

The responsibility of the primary care pediatrician is to

- Ensure that newborn screening has been conducted and that results are known, documented, and discussed with the family/caregiver.
- Inform, educate, and serve as a resource for parents, guardians, and families.
- Facilitate repeat or confirmatory testing and appropriate subspecialty referral.
- Initiate timely treatment and report information to newborn screening programs and public health agencies as necessary.
- Coordinate and manage long-term care for newborns affected by congenital conditions that are identified through newborn screening.

There is variation in how states communicate screening results with families, primary care pediatricians, and specialists. In the midst of a major disaster, usual methods of conveying out-of-range test results by phone, e-mail, and fax are typically not available. Follow-up during and after an emergency that requires evacuation of the patient’s home or city will further complicate communication mechanisms. Online retrieval of newborn screening results is the most desirable method during such emergencies. Pediatricians who are familiar with their state practices and contingency plans will find it easier to support families when there is a disruption in service.

Pediatricians can improve contingency planning by checking with their office staff to make sure that everyday office procedures are robust and well established. Procedures

should include routine protocols for checking all newborn screening results within 2 to 4 days and confirming that key contact information for notification of newborn screening results is on file. Developing a written plan that lists the contacts and describes what usually happens and what might need to take place in an emergency is important. Here are questions to guide discussions in pediatric office practices.

- Who are the key newborn screening program contacts in the state? Do office staff know of ways to contact them in the event of a disaster?
- What is the usual notification process? Are test results provided even when the results fall within normal ranges? Or does follow-up occur only when results are outside of normal ranges? What steps does the screening coordinator (or other state representative) take to notify pediatric offices or family members?
- What are the state procedures or typical plans for follow-up (eg, repeat screening, subspecialty care or referral)?
- Who are staff in the office who understand the screening results notification process? (There should be at least 2 people.)
- How can current procedures be changed to reinforce critical messages for expectant parents? (For example, has screening been conducted in the hospital? What test results are available to parents before discharge? How will the parent be informed of test results after discharge?) Are there times when the hospital or pediatrician can talk to parents about newborn screening before the baby is born? If the practice is located in an area prone to storms, power outages, or natural disasters, should more proactive communication be considered, perhaps as part of the prenatal visit?
- What can be done to establish a process to actively check for newborn screening results? This is a quality assurance approach that verifies that all babies have been screened (rather than assuming “no news is good news”). This will help pediatricians to know who has been screened and will enable office staff to get results and follow up appropriately.
- Are office staff able to connect with patients’ families during a disaster, perhaps by posting information on a practice Web page or via social media? Are alternative contact methods in patients’ records (eg, e-mail, cell phones for family members)?
- Are office staff encouraged to develop their own family preparedness plans?

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COMMUNICATING WITH FAMILIES

Identifying and addressing family concerns are essential activities of a high-quality, family-centered, and culturally competent medical home. Communicating with families about newborn screening is important to ensure that parents understand what the newborn screening process is and how they can help, especially in a disaster situation. Discussions about screening results can cause families to be worried about the health of their child. When a pediatrician talks to families about newborn screening results in a disaster situation, parents will likely become even more anxious. It is important to listen actively and communicate empathetically about all newborn screening processes and results—including in-range dried blood spot and pass results—while sharing complete, unbiased, and transparent information in a timely manner.

Pediatricians can provide anticipatory guidance to help children and families before and after a disaster. Research shows that when physicians talk to families about preparedness, they are much more likely to take action. After a disaster, children and families may experience post-event adjustment reactions, including stress, depression, anxiety, regression, somatic symptoms, bereavement, or post-traumatic stress disorder. Pediatricians are encouraged to take time to ask families how they are coping and offer reassurance and guidance, with a referral to a counselor or mental health professional as needed. This mental health support builds on the accepted principles of Psychological First Aid usually provided by trained laypersons after disasters but capitalizes on the preexisting and longitudinal relationship between family and the medical home, as well as the advanced clinical expertise of the pediatrician.

Pediatricians respond competently to behavioral and mental health issues in daily practice. Working with families and their response to an out-of-range screening result may prove complicated during an emergency. Even a simple inquiry about a family’s experience demonstrates empathy and concern and reassures the family of the pediatrician’s desire to help. Clinical recognition of the congenital conditions identified through newborn screening is critical in providing increased opportunities for positively affecting the lives of children and their families.

Pediatricians may wish to partner with obstetricians to discuss collaborative solutions for addressing various scenarios. Patient registries or a database to identify families with children with special health care needs might also be useful to facilitate identification of children at highest risk in an emergency.

Pediatricians, pediatric care professionals, and office staff can improve disaster planning for the office. Consideration of newborn screening contingency planning can result in improved preparedness and enhanced outcomes for affected children.

LEARN MORE

American Academy of Pediatrics Resources

Clinical report: “Newborn Screening Expands: Recommendations for Pediatricians and Medical Homes—Implications for the System”
<http://pediatrics.aappublications.org/content/121/1/192.full>

EQIPP course: “Newborn Screening: Evaluate and Improve Your Practice”
<http://eqipp.aap.org/home/myeqippcoursedetails?guid=ae762fff-c587-4eed-90bf-345c5469a62f>

National Center for Medical Home Implementation
<http://medicalhomeinfo.org>

Newborn screening
www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/pages/Newborn-Screening.aspx

Pediatric Preparedness Resource Kit
www.aap.org/disasters/resourcekit

Preparedness Checklist for Pediatric Practices
www.aap.org/disasters/checklist

Promoting adjustment and helping children cope
www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Children-and-Disasters/Pages/Promoting-Adjustment-and-Helping-Children-Cope.aspx

Quality report: “Improving Newborn Screening Follow-up in Pediatric Practices: Quality Improvement Innovation Network”
<http://pediatrics.aappublications.org/content/130/3/e669.long>

Supplement article: “Status of Newborn Screening Programs in the United States”
http://pediatrics.aappublications.org/content/117/Supplement_3/S212.full

Other Resources

Baby’s First Test
www.babysfirsttest.org/newborn-screening/states

National Coordinating Center for the Regional Genetic Service Collaboratives
www.nccrcg.org

National Newborn Screening & Global Resource Center
<http://genes-r-us.uthscsa.edu/resources/consumer/statemap.htm>

Newborn Screening Contingency Plan
www.cdc.gov/ncbddd/documents/NBS-CONPLAN.pdf

NewSTEPS
<https://newsteps.org>

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NEWBORN SCREENING OPPORTUNITIES WITHIN THE CONTEXT OF THE MEDICAL HOME

Hospital or Birthing Facility

- Conduct newborn screening and testing.
- Send specimens and data to screening laboratory.
- Clarify expectations with parents and pediatricians.

Screening Laboratory

- Input information into databases.
- Engage newborn screening coordinator to communicate results to parents and medical home.

Medical Home 3- to 5-Day Primary Care Health Supervision Visit

- Conduct recommended developmental surveillance and physical examination; attend to red flags for dried blood spot and congenital hearing and heart conditions.
- Confirm which newborn screening tests were conducted.
- For tests not yet done, arrange for screening and testing.
- Document results in patient files; reassure and educate parents.
- Report information to newborn screening programs and public health agencies as needed.

Patients/Families

- Discuss newborn screening (what to expect, how to be proactive) with the pediatrician.
- Confirm which newborn screening tests were conducted with hospital staff. Ask how results will be conveyed and to whom.
- Take notes when results are confirmed.
- Ask pediatrician if screening results are documented in the baby’s medical record.
- Follow up as requested with the pediatrician and medical subspecialists.

Medical Home Preparatory Work

- Review office protocols.
- Discuss ways to enhance existing newborn screening protocols.
- Identify relevant state contacts and existing contingency plans.
- Write out description of what usually happens.
- Implement office registry to track pregnant patients (partner with OB-GYN offices).
- Discuss newborn screening (what to expect, how to be proactive) with expectant parents.

Medical Home Follow-up

- Refer parents as needed to medical subspecialists.
- Offer parent education.
- Enhance pediatrician or office staff understanding of newborn screening topics.
- Determine how to close the loop to confirm screening has occurred and results are on file.