
Newborn Screening for Neonatal Hyperbilirubinemia

A Summary of the Evidence and Advisory Committee
Decision

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EXECUTIVE SUMMARY

This summary reviews the information the federal advisory committee used when deciding whether to recommend adding neonatal hyperbilirubinemia (NH) to the Recommended Uniform Screening Panel (RUSP) in 2012.

About the condition

NH is a condition in which babies have too much bilirubin in their blood. The body makes bilirubin when it breaks down blood cells. When too much builds up, it can damage brain cells. Between 3-12 out of every 100,000 babies develop severe NH. NH does not always cause disease. Severe NH can lead to serious health problems like permanent brain damage.

Treatment for NH

Early diagnosis allows early treatment. Treatments for NH include light therapy and exchange transfusion. These treatments may prevent serious health problems caused by high bilirubin levels.

Detecting NH in newborns

Newborn NH screening can happen during the first days of life at the bedside or in the nursery. To screen for NH, doctors and nurses can check newborns for yellow skin or eyes. This visual check does not measure exact bilirubin levels and can be inaccurate. Screening with a painless skin sensor or blood sample to measure exact bilirubin levels before a newborn leaves the hospital is advised. Newborns with high bilirubin for their age have NH. They need treatment and close follow-up.

Public health impact

Based on what is known about screening and the risk of severe NH, experts think that screening bilirubin levels in all newborns in the United States could prevent up to 108 cases of permanent brain damage each year. However, most newborns already get NH screening as part of their usual care.

Committee decision

The Committee voted in 2012 to recommend not adding NH to the RUSP because most newborns were already receiving this screening.

ABOUT THIS SUMMARY

What is newborn screening?

Newborn screening is a public health service that can change a baby's life. Newborn screening involves checking all babies to identify those few who look healthy but who are at risk for one of several serious health conditions that benefit from early treatment.

Certain serious illnesses can be present even when a baby looks healthy. If the baby does not receive screening for these illnesses early in life, a diagnosis may be delayed. Later treatment might not work as well as earlier treatment. Newborn screening programs have saved the lives and improved the health of thousands of babies in the United States (US).

Who decides what screening newborns receive?

In the US, each state decides which conditions to include in its newborn screening program. To help states determine which conditions to include, the US Secretary of Health and Human Services provides a list of conditions recommended for screening. This list is called the Recommended Uniform Screening Panel (RUSP).

Progress in screening and medical treatments can lead to new opportunities for newborn screening. To learn how a condition is added to the RUSP, see **Box A**.

What will this summary tell me?

In 2010, the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) requested an evidence review of newborn screening for neonatal hyperbilirubinemia (NH). This summary presents key review information that the Committee used to make its decision about whether to recommend adding NH to the RUSP. It will answer these questions:

- [What is NH?](#)
- [How is NH treated?](#)
- [How are newborns screened for NH?](#)
- [Does early diagnosis or treatment help patients with NH?](#)
- [What is the public health impact of requiring newborn NH screening in the US?](#)
- [What did the Committee decide about adding NH to the RUSP?](#)

Box A: Adding a Condition to the RUSP

A committee, called the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), makes a recommendation to the US Secretary of Health and Human Services about adding specific conditions to the RUSP. The Committee bases its decision on a review of the Condition, the screen, the treatment, and the ability of newborn screening programs to check for the condition. To learn more about the ACHDNC, visit this [website](#).

UNDERSTANDING THE CONDITION

What is neonatal hyperbilirubinemia (NH)?

NH is a condition in which babies have too much of a chemical called bilirubin in their blood. The body makes bilirubin when it breaks down blood cells. Babies with NH have trouble getting rid of this chemical, causing it to build up in the blood and body. When too much builds up, it can damage brain cells. Without treatment, severe NH may lead to permanent brain damage.

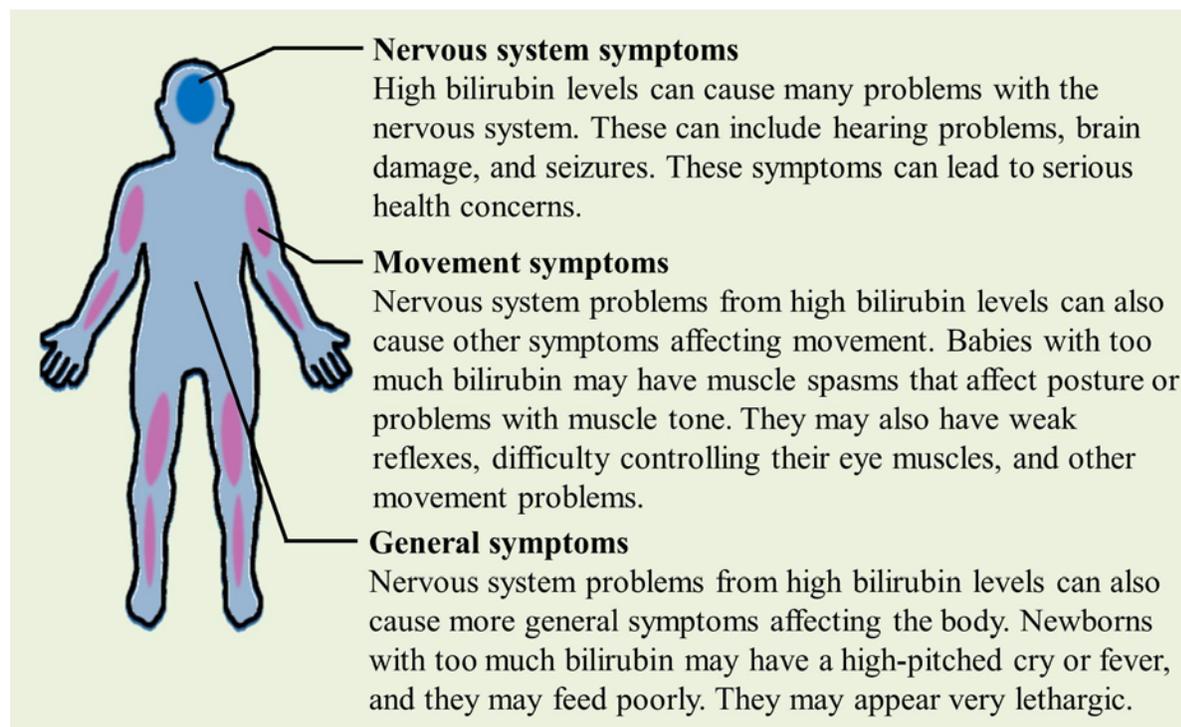
How common is NH?

- Many babies have high bilirubin levels in the blood. Between 3-12 out of every 100,000 children develop very high levels (severe NH).
- Certain factors increase the risk of severe NH. Babies born early (premature) and babies with a different blood type from their mothers have a higher risk of severe NH.

What kinds of health problems does NH cause?

NH can cause short-term skin yellowing (jaundice). Severe NH can cause serious problems with the nervous system (Figure 1).

Figure 1: Symptoms of Severe NH.



Does NH always cause disease?

No. Most babies with NH have no or only mild symptoms. Others have severe symptoms. Severe NH can sometimes lead to serious diseases:

- **Acute bilirubin encephalopathy (ABE).** Babies with ABE have problems with feeding, muscle tone, posture, reflexes, and lethargy. Other symptoms include a high-pitched cry, fever, and seizures. Symptoms from ABE can come and go. About 5 out of every 100,000 newborns develop ABE.
- **Chronic bilirubin encephalopathy (CBE).** Babies with CBE have brain damage causing problems with hearing, movement, eye control, and thinking. They may also have problems with tooth enamel. Symptoms from CBE are permanent. About 1 out of every 100,000 newborns develops CBE.

Babies with severe NH can develop ABE, CBE, or both. Having severe NH does not mean that a baby will develop ABE or CBE. However, ABE and CBE only occur in babies with severe NH.

When do NH symptoms develop?

NH can cause symptoms starting within the first days of life (Table 1).

Table 1: Symptom Timing and Type.

Age	Condition	Details
First days of life	NH	<ul style="list-style-type: none">● All newborns make bilirubin in their blood, but their bodies have trouble removing it. This makes their skin look yellow.● Rarely, severe NH can cause health problems like ABE or CBE. Treatment may prevent ABE and CBE.● In the second week of life, newborns look less yellow as their bodies begin to handle bilirubin better.
Early infancy	ABE	<ul style="list-style-type: none">● Some babies with severe NH develop ABE. The main cause of ABE is high levels of blood bilirubin. Other risk factors include premature birth and serious infection.● Without treatment, ABE may get worse with time and lead to CBE. Prompt treatment can improve ABE symptoms.
Early infancy to adulthood	CBE	<ul style="list-style-type: none">● Some babies with severe NH develop CBE.● Not all babies with CBE have ABE. Like ABE, the main cause of CBE is high levels of blood bilirubin. Other risk factors include premature birth and serious infection.● Brain damage from CBE is permanent. Children with CBE have symptoms for life.

TREATMENT FOR NH

How is NH treated?

Two treatments can prevent or even reverse some NH symptoms.

- **Light therapy**

This type of therapy is also called “phototherapy.” It involves shining special blue lights on babies with NH. The lights help the body break down extra bilirubin. This lowers bilirubin levels and reduces the risk of symptoms and ABE/CBE.

- **Exchange transfusion**

This type of therapy involves replacing some of a baby’s blood with blood from a healthy donor. This process lowers bilirubin levels and reduces the risk of symptoms and ABE/CBE. Only babies with very severe NH need this treatment.

What are the risks of treatment for NH?

- **Light therapy**

This is a safe treatment. Light therapy can be done in the hospital or at home. The main risk of light therapy is fluid loss. Doctors cover a baby’s eyes and monitor the baby during treatment to prevent problems.

- **Exchange transfusion**

This is a serious procedure. It can lead to breathing problems, blood clots, infections, or changes in blood chemistry. Because of these risks, only babies with dangerously high bilirubin levels get this treatment.

FINDING NEWBORNS WHO HAVE NH

How are newborns screened for NH?

Newborn screening for NH can happen during the first days of life at the bedside or in the nursery. It is not part of routine, blood spot-based screening. However, some of the blood taken for routine screening can also be used to screen for NH.

To screen for NH, doctors and nurses can check newborns for yellow skin or yellow eyes. This visual check does not measure exact bilirubin levels and can be inaccurate. To measure exact bilirubin levels, doctors and nurses often use a painless skin sensor or take a blood sample. Screening for NH using a blood sample is the most accurate method.

Doctors use a baby's age in hours and weeks of gestation to interpret NH screening results. Newborns with high bilirubin levels have NH.

How well does screening for NH work?

Experts think that screening for bilirubin in the blood detects most babies with NH. However, this process cannot tell which babies will develop ABE or CBE.

Because bilirubin levels can change in the first days of life, newborns have close NH monitoring early in life. This is one reason why many newborns have a check-up shortly after leaving the hospital.

What happens if newborn screening indicates NH?

Babies whose screening results reveal NH need more testing. This testing can involve a blood test to check or recheck bilirubin levels. Blood tests can also look for certain markers that raise a baby's risk for NH.

The next steps depend on the baby's bilirubin level, age, and other risk factors. Babies with very high bilirubin levels need treatment right away. They might also need more tests to measure bilirubin over time, look for other diseases, and determine the best treatment.

What are some of the benefits and risks of newborn NH screening?

Table 2 describes the benefits and risks of newborn NH screening as of 2012.

Table 2: Benefits and Risks of Screening.

Benefits	Risks
<ul style="list-style-type: none">● Earlier detection of babies with NH.	<ul style="list-style-type: none">● NH screening can require taking blood. This process can cause pain.● Some babies with normal bilirubin at screening may develop NH later. Screening might offer false reassurance in these cases.
<ul style="list-style-type: none">● Earlier symptom and bilirubin monitoring.	<ul style="list-style-type: none">● NH does not always cause serious symptoms or ABE/CBE.● The need for monitoring can make families worry.
<ul style="list-style-type: none">● Earlier treatment, which can reduce the risk of symptoms and ABE/CBE.	<ul style="list-style-type: none">● Earlier exposure to risks from treatment.

Do early diagnosis and treatment help patients with NH?

Yes. Experts know that:

- Early diagnosis allows early treatment.
- Treatment for severe NH works better before ABE or CBE develops.
- Early treatment with light therapy can lower bilirubin levels. It also lowers the need for exchange transfusion.

Box B: Where Can I Learn More?

Follow the links below to learn more about topics from this summary.

- To learn more about NH, visit the [Centers for Disease Control and Prevention Jaundice & Kernicterus](#) page.
- Visit the Committee’s website to learn more about:
 - [Nominating conditions to the RUSP.](#)
 - [Full NH evidence report.](#)
 - [The ACHDNC recommendation to the Secretary not to add NH to the RUSP.](#)

PUBLIC HEALTH IMPACT

How would newborn NH screening affect the health of the country?

Based on what is known about screening and the risk of severe NH, experts think that screening all newborns in the US for NH would prevent between 20 and 108 cases of CBE each year.

However, the American Academy of Pediatrics (AAP) already recommends that hospitals check newborns for NH before they leave the hospital. Most hospitals follow this guidance, so most newborns already get NH screening.

What is the status of newborn NH screening in the US?

- The AAP recommended in 2004 that all newborns have NH screening before they leave the hospital.
- Data on state readiness to begin newborn NH screening were not available at the time of the report.
- At the time of the report, no states had laws requiring newborn NH screening. However, most hospitals do follow the AAP guidelines and check all newborns for NH before they go home.

ADVISORY COMMITTEE DECISION

What did the Committee recommend?

The ACHDNC voted in 2012 to recommend that NH not be added to the RUSP. The Committee recognized that NH is important but that most newborns are already checked for it. The ACHDNC did not find enough evidence to show that adding NH to the RUSP would improve health outcomes.

HELPFUL INFORMATION

Glossary

Term	Definition
AAP	<u>A</u> merican <u>A</u> cademy of <u>P</u> ediatrics.
ABE	<u>A</u> cute <u>b</u> ilirubin <u>e</u> ncephalopathy. A condition that can cause problems with feeding, muscle tone, posture, reflexes, and lethargy.
ACHDNC	<u>A</u> dvisory <u>C</u> ommittee on <u>H</u> eritable <u>D</u> isorders in <u>N</u> ewborns and <u>C</u> hildren. The committee that oversees the RUSP.
Bilirubin	A chemical the body makes as it breaks down blood cells.
CBE	<u>C</u> hronic <u>b</u> ilirubin <u>e</u> ncephalopathy. A condition that can cause brain damage leading to problems with hearing, movement, eye control, and thinking.
Exchange transfusion	A treatment that replaces some of a baby's blood with blood from a healthy donor.
Jaundice	Yellow coloring of the skin or eyes.
Light therapy	A treatment that involves shining special blue lights on an infant's body.
NH	<u>N</u> eonatal <u>h</u> yperbilirubinemia. A condition in which babies have high bilirubin levels in the blood.
RUSP	<u>R</u> ecommended <u>U</u> niform <u>S</u> creening <u>P</u> anel. The list of conditions recommended for newborn screening.
Secretary of Health and Human Services	The head of the US Department of Health and Human Services. This person decides whether to add conditions to the RUSP.
Specialist	A doctor with expertise in a specific area of medicine.

Source

The information in this summary comes from the report *Evidence Review: Neonatal Hyperbilirubinemia* (05 January 2012), commissioned by the ACHDNC. The report reviewed data on NH screening and treatments in children through October 2011. It included both published and unpublished research. To see a copy of the full report, visit this [page](#).