



***Answers To  
Common  
Questions  
About  
Newborn  
Screening***

The New England Newborn Screening Program  
University of Massachusetts Medical School  
State Laboratory Institute  
305 South St  
Jamaica Plain, MA 02130  
(617) 983-6300

A Program of the  
Massachusetts Department of Public Health

This brochure contains important information about newborn screening for your baby.  
It is available in other languages  
<http://www.umassmed.edu/nbs/>  
617-983-6300

## SUMMARY

You may find that this summary is enough for you to make your decisions about newborn screening for your baby. More information may be found inside.

### **Newborn Screening helps to prevent certain treatable diseases.**

- Most likely, your baby will be healthy and you will never think twice about the diseases that are detectable with newborn screening.
- For the small number of babies who do have one of these diseases, newborn screening can make a lifetime of difference.

### **Newborn screening works by testing *all* babies who are born in Massachusetts.**

- Testing all babies is important, because most babies appear healthy at birth, even the babies who have diseases that can be detected by newborn screening.
- The testing for newborn screening is done on a few small drops of blood that are collected when your baby is about two days old.
- If testing shows that your baby has signs of one of these treatable diseases, your baby's doctor will call you to arrange appropriate care for your baby.

### *ROUTINE NEWBORN SCREENING*

- In Massachusetts, there are ten treatable diseases that are included in ROUTINE NEWBORN SCREENING.
- Under Massachusetts law, it is a requirement that *all* babies born in Massachusetts be screened for signs of these ten diseases unless parents object on the basis of religious beliefs.

### *OPTIONAL NEWBORN SCREENING*

- For your benefit, Massachusetts is offering newborn screening for an additional twenty disorders.
- ***There is no extra cost and no extra blood required for your baby to participate.***
- The OPTIONAL NEWBORN SCREENING is two research studies to develop the best screening programs for the additional twenty disorders.
- Under Massachusetts guidelines for the OPTIONAL PROGRAM, after your baby is born, you will be asked whether you want to take advantage of the OPTIONAL NEWBORN SCREENING.
- If for some reason, you decide that you do not want to participate in the OPTIONAL program, your baby will still have all the benefits of ROUTINE NEWBORN SCREENING.

**INTERESTED IN MORE INFORMATION ABOUT ROUTINE OR OPTIONAL NEWBORN SCREENING? LOOK INSIDE. THE TABLE OF CONTENTS IS YOUR GUIDE TO COMMON QUESTIONS ABOUT THESE PROGRAMS.**

Dear Parent,

*Congratulations! As you look to the future with your new baby, you will be happy to know that all babies born in Massachusetts benefit from a public health program called Newborn Screening. This program helps prevent treatable diseases. It started in 1962 in Massachusetts with screening for just one disease. Since that time, the number of treatable disorders in the program has increased and newborn screening has been adopted worldwide as a routine standard of care. Massachusetts is a leader in newborn screening: Massachusetts offers routine screening for more treatable disorders than any other program.*

*Massachusetts also offers you some optional screening services. After your baby is born, you will be asked whether you want to take advantage of the optional services (see details below; also p.9).*

*This booklet is your guide to Newborn Screening. A summary is provided on the inside cover to your left. This booklet has additional descriptions of both Routine and Optional screening (see TABLE OF CONTENTS, next page).*

*We wish you and your baby the very best.*

*Sincerely,*

*The Staff of The New England Newborn Screening Program*

**How do I enroll? Or how do I refuse to participate?**

After your baby is born, you will be asked whether you received this brochure with information about the pilot studies. Then, you will be asked whether you want your baby to be screened for the disorders in the two pilot programs.

*Important! You will be asked to give your response before your baby's specimen is sent to the screening lab\*. Your answer will be indicated on the newborn screening collection form. When your answer is recorded on your baby's specimen collection form, you will be given a copy to keep for your records. A sample of the copy you will receive is shown below. (Note: you may be reading a non-English translation of this brochure. However, the actual copy for your records would be in English.)*

*\*Specimens are obtained between 24-72 hours after birth, or prior to discharge if discharge is earlier than 24 hours. In order to ensure that routine newborn screening of your baby for the 10 mandated disorders is not delayed, the specimen must be collected and transported promptly.*

PARENT'S COPY	LAB ID # 100001	<input type="checkbox"/> declines CF	<input type="checkbox"/> declines MET
	BABY'S NAME	(Last)	(First)
Dear Parent			
This sheet is your record to show that a small blood specimen was taken from your baby for routine newborn screening. This routine service ensures that your baby will be screened for each of 10 treatable disorders as mandated by the Massachusetts Department of Public Health.			
In addition, this sheet records your instructions to your hospital nursery/pediatrician on your decisions about optional services (public health research initiatives) that are being made available to all babies born in Massachusetts.			
<ul style="list-style-type: none"><li>• If your sheet has an X in the "declines CF" box, your baby will NOT be screened for cystic fibrosis.</li><li>• If your sheet has an X in the "declines MET" box, your baby will NOT be screened for any of the new set of 19 metabolic disorders.</li></ul>			
The New England Newborn Screening Program of the University of Massachusetts Medical School provides all newborn-screening services, as described in your brochure entitled "Answers to Common Questions About Newborn Screening".			
<b>New England Newborn Screening Program, University of Massachusetts Medical School</b> 305 South St., Jamaica Plain, MA 02130 (617) 983-6300			

## **ROUTINE SCREENING**

### **What is the purpose of the Newborn Screening Program?**

The purpose of the Newborn Screening Program is to test all newborns in Massachusetts for early signs of a number of treatable disorders (as mandated by Massachusetts Department of Public Health Regulations 105 CMR 270.000.)

This brochure describes these disorders and explains why your baby needs to be tested.

### **What is the chance my baby has a disorder detectable by screening?**

The chance that your baby will have one of these disorders is very small. In the rare cases when a disorder is found, early diagnosis and treatment can usually prevent the problems associated with these disorders.

Newborn screening tests provide an early opportunity to detect certain disorders before symptoms appear. However, screening tests are not always accurate and may not detect a disorder. In any case, if your baby does not seem well, talk to your baby's doctor as soon as possible.

### **How are the tests done?**

At about 48 hours after birth, or just before your baby is discharged from the hospital, a small blood sample will be taken. Only a few drops of blood are needed. These are taken from your baby's heel.

*Important!* Babies born outside of hospitals should also be tested, preferably at about 48 hours after birth. Parents should arrange with a doctor, hospital, or midwife to have the screening done.

## For which treatable disorders will my baby be screened?

Your baby will be screened for early signs of the following 10 disorders:

- 1. Congenital Hypothyroidism** <http://www.magicfoundation.org/congthyr.html>.  
This disorder is caused by the lack of thyroid hormone, which can lead to poor growth and mental retardation. If found early and treated with thyroid medication, a child will grow and develop normally.
- 2. Phenylketonuria (PKU)** <http://www3.ncbi.nlm.nih.gov/htbin-post/Omim/dispim?261600>.  
This disorder is caused when a baby's body is not able to break down the amino acid, phenylalanine, which is found in the protein of foods. If detected early and the baby is started on a special low phenylalanine diet, mental retardation is prevented.
- 3. Hemoglobin Disorders** <http://www3.ncbi.nlm.nih.gov/htbin-post/Omim/dispim?141900>.  
These disorders include Sickle Cell Disease, a condition caused by a change in the red blood cells. It means the baby is more likely to have anemia, episodes of pain, strokes, and life-threatening infections. Treatment with penicillin may prevent serious infections in early childhood.
- 4. Congenital Toxoplasmosis**  
[http://www.noah.cuny.edu/pregnancy/march\\_of\\_dimes/pre\\_preg\\_plan/toxoplas.html](http://www.noah.cuny.edu/pregnancy/march_of_dimes/pre_preg_plan/toxoplas.html).  
This disorder is an infection that can be either mild or severe. In a young baby, this infection may lead to mental retardation, blindness, and other defects. Early treatment with medications may reduce the risk of serious problems.
- 5. Biotinidase Deficiency** <http://www3.ncbi.nlm.nih.gov/htbin-post/Omim/dispim?253260>.  
The disorder is caused by the lack of an enzyme called biotinidase. This disorder can lead to seizures, developmental delay, eczema, and hearing loss. Problems can be prevented with biotin treatment.
- 6. Galactosemia** <http://www3.ncbi.nlm.nih.gov/htbin-post/Omim/dispim?230400>.  
This disorder occurs when a baby cannot break down the galactose part of milk sugar. In some cases, life threatening damage to the brain and liver can occur as early as one week after birth. When started early, a special milk-free diet prevents these problems.
- 7. "Maple Syrup" Urine Disease (MSUD)**  
<http://www3.ncbi.nlm.nih.gov/htbin-post/Omim/dispim?248600>.  
This disorder is caused by not being able to break down several amino acids. It can result in mental retardation, seizures, or death. The name of the disorder comes from the distinctive maple syrup odor of the urine. When detected early, infants are put on a special diet to avoid the severe effects of the disease.
- 8. Homocystinuria** <http://www3.ncbi.nlm.nih.gov/htbin-post/Omim/dispim?236200>.  
This disorder is caused by not being able to break down the amino acid, methionine. This disorder can lead to mental retardation, eye problems, and blood clots. When detected early, infants are put on a low methionine diet to avoid these problems.
- 9. Congenital Adrenal Hyperplasia**  
<http://www3.ncbi.nlm.nih.gov/htbin-post/Omim/dispim?201910>.  
This disorder is caused by the lack of an enzyme that the adrenal gland uses to process hormones. In girls, the genitalia may appear as male. Serious loss of body salt and water, even death, may occur in either sex. Treatments are available to correct the condition.
- 10. Medium-chain acyl Co-A dehydrogenase deficiency (MCAD)**  
<http://www3.ncbi.nlm.nih.gov/htbin-post/Omim/dispim?201450>.  
This disorder can cause metabolic crisis when an infant "fasts" (goes for a long period of time without eating, such as during an illness). This kind of metabolic crisis can sometimes lead to seizures, failure to breathe, cardiac arrest and death. The main focus of treatment is to prevent a metabolic crisis from happening. Treatment is effective and focuses on preventing long fasts.

**Other.** There are other disorders for which you can choose to have screening (see section called OPTIONAL SCREENING, Research Studies of New Tests)

## Who decides which disorders are included in Newborn Screening?

The Commissioner of Public Health is responsible for deciding the list of disorders. An Advisory Board, made up of doctors, nurses, scientists, ethicists and consumers, advises the Commissioner which disorders to include. For a disorder to be included in the list, the following must be true: 1) the disorder is treatable, 2) there is a good test, 3) early medical intervention would benefit the infant.

## May I refuse these tests?

Most states have specific laws regarding newborn screening. In Massachusetts you may refuse for religious reasons. If you do so, you may be asked to sign a refusal form. This form relieves your doctor of liability for damages that result from a disorder that could have been detected by screening.

## How are results reported and how would I be notified if my baby needs special care?

Your baby's test results will be reported to the hospital where your baby was born. These reports include results of all routine testing and results of any optional screening your baby had (see section entitled "Research Studies of New Tests") .

In addition, if your baby's test results indicate that further attention is needed (see below), the hospital where your baby was born or your baby's doctor will be notified.

## I was called and told that my baby's test needs to be repeated. Does that mean that my baby has a disorder?

Not always. There are several reasons why your baby's doctor may have told you that your baby needs to be retested. Some reasons include:

**Unsatisfactory specimen:** There is not enough blood to complete all the required screening tests, or the sample does not work for other reasons.

**"Too Early" specimen:** If the blood specimen was collected before your baby was 24 hours old, a second sample should be taken as soon as possible to avoid missing a disorder. The best time for detection is between 24 and 72 hours after birth.

**Abnormal Test Result:** An abnormal test result means that a disorder *may* be present. If the repeat test indicates that further evaluation is needed, your baby's doctor will be called right away.

*Note:* Premature or low birth weight newborns are more likely to have abnormal test results on the first specimen even if a disorder is *not* present.

## **OPTIONAL SCREENING**

### **Research studies of new tests (Pilot studies):**

The Massachusetts Department of Public Health may authorize and direct research studies of new tests in the Newborn Screening Program. Research studies of new tests, called pilot studies, are done when the Department of Public Health expects they could benefit both individuals and the public health. *No additional blood will be taken from your baby*, but these tests will screen for a number of disorders in addition to the routine testing already described.

Results of pilot studies are reported with routine screening results. As with routine newborn screening, if there was an abnormal result, your baby's doctor would work with the right specialists to manage any special care that your baby might need.

### **What pilot studies are being done now?**

Beginning February 1, 1999, the Program is conducting two pilot studies called:

- [Newborn Screening for markers of cystic fibrosis](http://www3.ncbi.nlm.nih.gov/htbin-post/Omim/dispim?219700)  
<http://www3.ncbi.nlm.nih.gov/htbin-post/Omim/dispim?219700>
- [Newborn Screening for a set of 19 additional metabolic disorders.](#)

### **Why is newborn screening for cystic fibrosis and the additional set of metabolic disorders being offered as pilot studies rather than being mandated like the other 10 disorders?**

There are three main reasons:

1. To evaluate the benefit of newborn screening in bringing babies with possibly serious medical conditions to early medical attention.
2. To find out how often these disorders occur in Massachusetts.
3. To evaluate the laboratory tests used to screen for these disorders.

### **Can any newborn participate in the pilot studies?**

Yes, any newborn who would be included in routine newborn screening on or after February 1, 1999 can participate.

## May I refuse to participate in one or both pilot studies?

Yes. You may refuse your baby's participation in either one or both of the pilot studies, for any reason. If you refuse, your baby will still have all the advantages of routine newborn screening.

## How do I enroll? Or how do I refuse to participate?

After your baby is born, you will be asked whether you received this brochure with information about the pilot studies. Then, you will be asked whether you want your baby to be screened for the disorders in the two pilot programs.

*Important! You will be asked to give your response before your baby's specimen is sent to the screening lab\*. Your answer will be indicated on the newborn screening collection form. When your answer is recorded on your baby's specimen collection form, you will be given a copy to keep for your records. A sample of the copy you will receive is shown below. (Note: you may be reading a non-English translation of this brochure. However, the actual copy for your records would be in English.)*

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In addition, this sheet records your instructions to your hospital nursery/pediatrician on your decisions about optional services (public health research initiatives) that are being made available to all babies born in Massachusetts.

- If your sheet has an X in the "declines CF" box, your baby will NOT be screened for cystic fibrosis.
- If your sheet has an X in the "declines MET" box, your baby will NOT be screened for any of the new set of 19 metabolic disorders.

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305 South St., Jamaica Plain, MA 02130 (617) 983-6300

## What are the general benefits and risks associated with the pilot studies?

### *Possible Benefits*

- The most important individual benefit for your baby is the following:  
If your baby does have one of the disorders included in the study, your baby will have the earliest opportunity for detection of the disorder and appropriate medical intervention.
- Other benefits may include your own satisfaction that you are helping to answer important questions that may help other babies.

### *Possible Risks*

As with any testing, this testing will have one of two possible results: your baby will have either a normal or an abnormal screening result. Each of these two results has its own risks that you may want to consider:

- If your baby has an *abnormal screening result*, it is possible that your baby actually does not have the disorder. To be sure, your baby's doctor may recommend further testing by a specialist who may take additional specimens (usually blood or urine) from your baby. Additional testing may cause you to worry, which is a common reaction to receiving results of tests in any screening program. If after further testing, you receive the happy news that your baby does not have the disorder, your baby's medical record should reflect the update, but you may want to make sure that this happens.
- If your baby has a *normal screening result*, there is still a chance that your baby has the *disorder* (i.e. for some reason, the disorder was not detected by the newborn screen). If healthcare providers were to rely too heavily on the screening result for diagnosis, it could delay early medical intervention. This risk exists for all forms of screening, including the new screening tests. In any case, *if your baby does not seem well*, you should talk to your baby's doctor as soon as possible.

## Where can I find out more about the Pilot studies?

See the next section, entitled "Additional information for parents who want to know more about the 2 pilot studies".

# Additional information for parents who want to know more about the 2 pilot studies

Pilot Study #1: Newborn screening for markers of cystic fibrosis (CF):

## **What is cystic fibrosis?**

Cystic fibrosis is one of the most common of the serious inherited disorders present in children. It can occur in all races. Children who have cystic fibrosis are born with the disorder, but often do not show visible signs of disease for weeks, months, or even years. In this disorder there are abnormal amounts of salt in body secretions, especially in the lungs and pancreas. In some people, the signs appear mainly in the lungs. In other people, the signs are mainly in the digestive system. In the lungs, airways become blocked and have too many bacteria. This leads to chronic infections, lung damage and death from lung failure. In the pancreas, when ducts are blocked there is a loss of digestive enzymes in the bowel. This leads to severe malnutrition. Medical treatment can include replacing digestive enzymes right away and use of antibiotics, and careful monitoring. This may improve growth and the long-term outcome in these patients.

## **What is the chance that my baby will have cystic fibrosis?**

In Massachusetts, approximately 1 of every 3,000 babies has cystic fibrosis.

## **What is the pilot program going to study?**

This study will focus on developing the best screening test for the early detection of newborns with cystic fibrosis. *No additional blood will be taken from your baby.* There will be a testing system like the one in Wisconsin, where pilot testing began. If your baby is screened, your baby's blood specimen will first be tested for a protein from the pancreas called IRT. If the test shows that your baby's IRT level is higher than normal, your baby's specimen will then be tested for a DNA marker that is associated with cystic fibrosis. If that DNA marker is found in your baby's specimen, the Newborn Screening Program will contact your baby's doctor about the result. Your baby's doctor would then contact you, and work with you to arrange for your baby to be seen by a Cystic Fibrosis specialist. This specialist will do a test to find out if your baby actually has cystic fibrosis.

## **Will the Massachusetts system of testing be exactly like the one in Wisconsin?**

No. We know from national and Massachusetts information that is gathered by the Cystic Fibrosis Foundation, that the test used in Wisconsin would miss a very high number of Massachusetts babies who have cystic fibrosis. The Massachusetts testing plan will look for more DNA markers. While the Wisconsin test works for Wisconsin, Massachusetts needs a test that is sensitive to the

racial and ethnic diversity of the Massachusetts population.

## **Will all babies who participate in the study be tested for DNA markers of cystic fibrosis?**

No. We expect one in ten babies will be tested for DNA markers of cystic fibrosis.

## **Will all babies who participate in the study need to be seen by a Cystic Fibrosis specialist?**

No. If your baby participates in the study, the chance that your baby would be referred to a cystic fibrosis specialist is about 0.3%, or 3 in 1,000.

## **If my baby is referred to a Cystic Fibrosis specialist, does that mean that my baby has cystic fibrosis?**

Not necessarily. For every 5 or 6 babies whose result indicates the need for referral to a cystic fibrosis specialist, only one of those babies will actually have cystic fibrosis.

## **If my baby is one of the babies who needs to be seen by a Cystic Fibrosis specialist, where would I find the specialist?**

Your baby's doctor would help you. Cystic fibrosis specialists are located at the five Cystic Fibrosis Centers in Massachusetts. These centers are certified by the Cystic Fibrosis Foundation to provide a full range of diagnostic, clinical and follow-up services. The 5 Massachusetts CF Centers are located across the state: three in Boston, one in Worcester, and one in Springfield. The New England Newborn Screening Program is working with all of these Centers to make sure that their services will be known to all families who need them.

## **Why are you asking me for a decision? Doesn't my baby's doctor know?**

There is good reason to believe that the program can work (testing is accurate) and that the program is worthwhile (benefits of early intervention outweigh the risks). However, before newborn screening for CF becomes routine, the Advisory Committee wants to study how the program will work best in Massachusetts. As a parent, you are being asked to decide whether you want to participate in this "pilot study". We expect that most parents will want their baby to have this test, but we understand that some parents might have personal reasons for not taking part in the pilot study. Because of this, the choice is being offered to you, rather than to your doctor or healthcare provider.

## Pilot Study #2 Newborn screening for a set of 19 additional metabolic disorders

### **Can you tell me more about what is included?**

The disorders include a variety of conditions that lead to a chemical imbalance in the body. The disorders can lead to vomiting, problems with salt and water balance, developmental problems, or even coma and death. Some of the conditions have better treatments available at this time than others. The outcome of treatment can range from good to poor and depends partly on how much harm occurred before treatment took place.

Some of the disorders have to do with the baby's problems in changing stored fat to a form (fatty acids) that can be used for energy. The names of these fatty acid disorders start with letters that describe the size of the fatty acids that occur in the chemical imbalance, for example *S* (short), *L* or *LCH* (long), *VL* (very long), or *M* (medium). The rate of the short and long types, taken together, is only one per 30,000 newborns and less is known about them than about the type of disorder with medium-size fatty acids, (*MCAD*). *MCAD* is now included in routine mandated screening. However, there is some proof that all types of these conditions may benefit from some of the same types of dietary management used for *MCAD*.

Body proteins are made up of building blocks called amino acids. Some of these amino acids are involved in a variety of the disorders included in this screening. For example, in the disorders called *tyrosinemia type I* or *tyrosinemia type II*, there is a buildup of the amino acid *tyrosine*. This is associated with liver failure (in type I) or problems with the eyes, skin, or general development (in type II). Treatment can range from special diets (in type I or II) to liver transplantation (in type I). Other amino acid disorders, called *argininemia*, *argininosuccinic aciduria*, *citrullinemia*, and "*HHH*" syndrome, are associated with toxic buildup of ammonia in the blood. This could lead to coma or death. Treatment is with a special diet and special medications.

Some of the other disorders are caused by buildup in the body of organic acids which can be toxic. Examples are *propionic acidemia*, or *methylmalonic acidemia*, *isovaleric acidemia* and *glutaric acidemias I* and *type II*. Vomiting, with loss of body fluids and salts, can lead to coma and death if untreated. Symptoms may begin as early as a few days after birth or not until months later. Treatment usually consists of a special diet and special medications.

### **What is the chance that my baby will have one of these 19 disorders?**

We really do not know how many Massachusetts babies have these 19 disorders. By doing this test, we estimate that we will detect 4-6 Massachusetts babies each year.

### **What is the pilot program going to study?**

The plan is to use new technology (called tandem mass spectrometry) to look at markers that can tell us which babies have disorders that have not been included in routine newborn screening. The study will find out how often these disorders occur in the Massachusetts population, and whether the technology is useful. *No extra blood will be taken from your baby.* Two types of natural chemicals, called amino acids and acyl carnitines, will be measured in your baby's blood. If these substances are found in unusual amounts in your baby's blood, the Newborn Screening Program will call your baby's doctor about the result. Your baby's doctor would then contact you, and work with you to arrange for your baby to be seen by a Metabolic Disease specialist. The specialist would perform further tests to find out whether or not your baby actually has one of the disorders.

### **If my baby is one of the babies who needs to be seen by a Metabolic Disease Specialist, where would I find the specialist?**

Your baby's doctor would help you. The New England Newborn Screening Program is working with a network of these specialists. Together they will make sure that the most up-to-date information available will be used to care for babies identified through this pilot study. If your baby's screening result indicates the need for a specialist, the Newborn Screening Program will make sure that your baby's doctor knows about these services.

### **Why are you asking me for a decision? Doesn't my baby's doctor know?**

There is good reason to believe that the program can work (testing is accurate) and that the program is worthwhile (benefits of early intervention outweigh the risks). But before a *requirement* for this additional newborn screening is recommended, the Massachusetts Newborn Screening Advisory Committee would like the answers to these questions:

- How many Massachusetts babies have these disorders?
- How much will babies benefit if they are identified by the Newborn Screening Program?
- Will the screening test be accurate and identify only those babies who have the disorders, without falsely identifying babies who do not have the disorder?

As a parent, you are being asked whether you want to participate in this "pilot study", to help find the answers to these questions. We expect that most parents will want to get this test for their baby, but we understand that some parents might have personal reasons for not taking part in the pilot study. Because of this, the choice is being offered to you, rather than to your doctor or healthcare provider.

**I have some suggestions, or I have some comments. How can I be make sure that my comments will be considered?**

You should address your written comments to any of the following committees or programs, and they will be reviewed by the Department's Newborn Screening Advisory Committee:

Chairperson  
Newborn Screening Advisory Committee  
Massachusetts Department of Public Health  
250 Washington St.  
Boston, MA 02108-4619

Commissioner of Public Health  
Massachusetts Department of Public Health  
250 Washington St.  
Boston, MA 02108-4619

Director  
New England Newborn Screening Program  
305 South St.  
Jamaica Plain, MA 02130