

Changes to the Newborn Screening Program as of April 1 2013



In Ibaraki Prefecture, newborn babies undergo the newborn screening test in order to detect congenital disorders as early as possible. Up until recently, the newborn screening test targeted six disorders. The tandem mass spectrometry method, which enables the detection of a wider range of disorders through a single test, was introduced on April 1 2013. As a result, the newborn screening test now targets the following 19 disorders:

Disorders targeted by the newborn screening test

Name of Disorder		How it works
Amino Acid Metabolic Disorders	phenylketonuria (PKU), maple syrup urine disease (MSUD), homocystinuria, type I citrullinemia, argininosuccinic aciduria	Babies with these disorders are unable to correctly utilize nutrients such as protein from their food, which may affect their growth and development and cause them to become ill.
Organic Acid Metabolic Disorders	methylmalonic acidemia (MMA), propionic acidemia, isovaleric acidemia, methylcrotonylglycinuria, hydroxymethylglutaryl (HMG) acidemia, multiple carboxylase deficiency, glutaric acidemia type 1	
Fatty Acid Metabolic Disorders	medium-chain acyl-CoA dehydrogenase (MCAD) deficiency, very-long-chain acyl-CoA dehydrogenase (VLCAD) deficiency, mitochondrial trifunctional protein (TFP)/ long-chain 3-hydroxyacyl-CoA dehydrogenase (LCHAD) deficiency, Carnitine palmitoyltransferase I (CPT-1) deficiency	
Carbohydrate Metabolic Disorders	Galactosemia	
Endocrine Disorders	congenital adrenal hyperplasia, congenital hypothyroidism	These disorders result in adrenocortical and thyroid hormone deficiency. Treatment by supplementing the deficient hormone through medication is necessary.

Early detection and treatment can prevent the onset of these disorders. However, in the most serious cases some disorders may begin to take effect before the test is performed, and sometimes treatment can be difficult. Even so, early diagnosis can reduce the severity of disability.

✿ How can I apply for the test?

If your child is born in a medical institution in Ibaraki Prefecture and you want the test performed, fill out the Newborn Screening Test Application Form and submit it to the medical institution where your child was born.

✿ How does the test work?

When the baby is 4-6 days old (on the day of birth, the baby is considered to be 0 days old), a very small amount of blood will be taken from the baby's heel at the medical institution where he or she was born and sent to a specialized screening facility. Babies who weigh less than 2000g at birth will be required to have a second test.

✿ How much does it cost?

The test is free. (If you give birth and take the test at a medical institution in Ibaraki Prefecture, the cost of the test will be borne by the prefecture). However, you will be required to pay to have the blood sample taken at the medical institution.



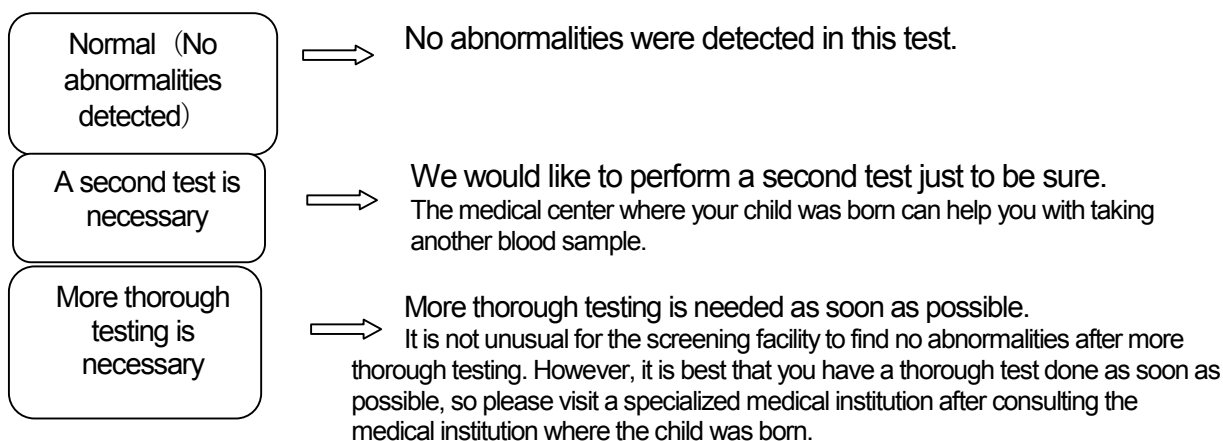
Important information regarding application for the newborn screening test

- ① In rare cases, the newborn screening test may not detect these disorders in your child, and in cases where the disorder takes effect immediately after your child is born, it may be too late.
- ② Personal information acquired for the purposes of the newborn screening test will not be used for anything other than the test. The blood sample and other information acquired for the test and will be stored for a period of three years, then disposed of in a way that prevents identification.
- ③ In cases where a second test or more thorough testing is required, we may need to contact the prefectural or municipal health center that has jurisdiction of the municipality in which you live.

When will I receive the result?

The test result will generally be sent to the medical institution where the blood sample was taken two weeks later. The medical institution will then relay the result to the baby's guardian(s). In Japan, it is customary for infants to have a health checkup when they reach one month of age, so please follow up on your result at this checkup or at a similar consultation with a doctor.

There are three types of result – “Normal (no abnormalities detected)” “A second test is necessary” and “More thorough testing is necessary”.



What happens if an abnormality is detected?

If your child is deemed to have a disorder, please visit a specialist to receive information about treatment and things you will need to consider in day to day life.

Furthermore, there is a welfare system in place for those with certain chronic childhood diseases to assist with medical fees, so please contact the prefectural health center in your municipality for more information.

Name of Health Center	Phone	Municipalities in its Jurisdiction
Mito Health Center	029-244-2828	Mito, Kasama, Omitama, Ibaraki-machi, Oarai, Shirosato
Hitachinaka Health Center	029-265-5647	Hitachinaka, Tokai-mura
Hitachiomiya Health Center	0295-52-1157	Hitachiota, Hitachiomiya, Naka, Daigo
Hitachi Health Center	0294-22-4192	Hitachi, Takahagi, Kita-Ibaraki
Hokota Health Center	0291-33-2158	Namegata, Hokota
Itako Health Center	0299-66-2118	Kashima, Itako, Kamisu
Ryugasaki Health Center	0297-62-2172	Ryugasaki, Toride, Ushiku, Moriya, Inashiki, Kawachi, Tone
Tsuchiura Health Center	029-821-5398	Tsuchiura, Ishioka, Kamisugaura, Miho, Ami
Tsukuba Health Center	029-851-9287	Tsukuba, Tsukuba-Mirai
Chikusei Health Center	0296-24-3911	Yuki, Chikusei, Sakuragawa
Joso Health Center	0297-22-1351	Shimotsuma, Joso, Bando, Yachiyo
Koga Health Center	0280-32-3021	Koga, Goka, Sakai

For more information about the Newborn Screening test, please contact a staff member in charge of maternal and child health at the Ibaraki Prefectural Government Children and Family Division (PH: 029-301-3257 direct line, Japanese only)