

Note Before Applying for Neonatal Screening

Please read the Neonatal Screening pamphlet and the following information before applying for neonatal screening for your baby. Fill out the attached application form and submit it to a medical institution.

1. Follow-up surveys

The City of Sapporo conducts follow-up surveys to evaluate the effectiveness of the neonatal screening and to observe whether patients are detected and provided with the appropriate medical treatment. The purposes of the follow-up surveys are to gather information of patients who were detected by neonatal screening to assess their treatment outcomes as well as to identify patients who have been missed by the screening.

2. Protection of personal information

Personal information acquired as a result of the screening and follow-up surveys is strictly protected in accordance with the Sapporo Ordinance on the Protection of Personal Information and the Sapporo Information Security Policy.

The results from the screening and follow-up surveys may be reported at academic conferences, published in scientific journals and the city's public relations magazines, or posted on the City of Sapporo website. Personal information such as the name of the baby will never be disclosed. The privacy of the baby and his/her family is strictly protected.

3. Handling of blood samples after examination

After the screening, blood samples will be kept as important specimens to be used in research for the improvement of neonatal screening methods and the development of screening methods for other diseases. The Ethics Committee of the Sapporo Institute of Public Health reviews and approves each research project for its purposes and appropriateness of the research methods and handling of samples. Evaluations made by the committee are available to the public on the City of Sapporo website.

Parents/guardians of the child receiving the screening are asked to consider donating the child's blood samples collected during the screening to the City of Sapporo for future research and indicate their agreement on the screening application form. The donated specimens will be stored for 10 years.

Applicants are always free to withdraw their consent by submitting the Consent Withdrawal Form found on the back of this sheet. Please fill out the form, cut along the dotted line and send it to the Institute of Public Health (to the contact address indicated below). Withdrawal will in no way influence the validity of the applicant's screening results or any other services they may seek in the future.

4. Examination using a new analysis method

In Sapporo, tandem mass spectrometry is used in the neonatal screening to increase the effectiveness of the screening. This screening method is recommended for all newborns as it offers screening for 20 additional diseases without increasing the burden on them.

The additional diseases to be screened for by tandem mass spectrometry include conditions which following the development of a cold may cause encephalopathy or sudden infant death (cot death). Early detection of such conditions by neonatal screening can prevent the onset of the diseases. However, some conditions detected by tandem mass spectrometry can be very serious with little chance of effective treatment, while at the same time some minor conditions may go undetected. There are some municipalities that have not yet introduced tandem mass spectrometry in their neonatal screenings.

Upon learning thoroughly about the conventional neonatal screening method and the tandem mass spectrometry (a new analysis method to screen regular screening items plus an additional 20 diseases), applicants who do not want to receive screening for the additional 20 diseases can opt for the conventional neonatal screening which only screens for the regular screening items. For those applicants who do not wish to be screened for the additional 20 diseases, please contact the Institute of Public Health.

Contact:

Institute of Public Health
Health Science Section (Maternal and Child Screening)
Kikusui 9-jo 1-chome, Shiroishi-ku, Sapporo 003-8505
Tel.: 011-841-7672

Please send the Consent Withdrawal Form to:
Institute of Public Health
Health Science Section (Maternal and Child Screening)
Kikusui 9-jo 1-chome, Shiroishi-ku, Sapporo 003-8505
Tel.: 011-841-7672

Consent Withdrawal Form

To the Mayor of Sapporo,

Date: _____

I gave my consent allowing the blood samples that were collected from the following described child for the purpose of neonatal screening to be used in other research purposes on _____ (date of consent), however, I hereby withdraw my consent.

Name of Child: _____ (Date of birth: _____)

Name of Parent/Guardian: _____ (Relationship to the child: _____)

Address: _____

Neonatal Screening Application Form

Date: _____

To the Mayor of Sapporo,

I have thoroughly read the Neonatal Screening pamphlet as well as the explanation on the sheet attached to this application form and received sufficient explanation from the medical institution. With my full understanding of these explanations, I hereby apply for the neonatal screening.

●Name of Parent/Guardian: _____
●Relationship to the child: _____
●Contact address: _____ _____
●Tel.: (_____) _____ - _____
●Child's date of birth: _____
●Name of medical institution (maternity hospital): _____

© Consent for the use of the blood samples collected during the neonatal screening in other research purposes

I hereby agree that the blood samples taken from my child will be stored at the Sapporo Institute of Public Health for up to 10 years and used in research for the improvement of neonatal screening methods and the development of screening methods for other diseases.

YES

NO

(Please circle)

*Personal information is strictly protected.

*The validity of the test results is in no way influenced by the applicant's agreement or refusal to donate his/her child's blood samples.