(B) Extended Hesse Screening Programme
In addition to the standard programme we also offer screening at no extra cost for 17 additional target diseases (see our website for disease descriptions: www.screening-hessen.de), the prompt diagnosis of which - according to scientific assessment - may improve the health prognosis of those children affected.

The extended Hesse screening programme therefore offers you newborn screening for a total of 31 target diseases.

Data and remaining blood samples
Pursuant to § 12 of the German Genetic Diagnostics Act (GenDG), the extended Hesse screening programme stores all data for 10 years.

Every scientific test conducted on blood samples within the scope of the Extended Hesse Screening Programme with the intention of promoting the development of said programme must be sanctioned by the Hesse Screening Centre Advisory Board, which includes representation from the Hesse Ministry for Social Affairs as well as the Hesse Data Protection Supervisor. The tests are conducted anonymously, making it impossible to know from which child the blood in question originates. Scientific tests that identify your child are only possible if you have given your prior written consent.

Remaining blood samples
Unused blood samples are destroyed after 3 months.

For those affected, newborn screening can have a lifetime impact!
It is therefore crucial that all children affected and in treatment receive optimum care for their entire life. The Hesse Screening Centre which forms part of the Hesse Paediatric Centre is happy to provide you and your medical practitioners with advice at all times.

From time to time we will contact the parents of sick children with offers of help and support. Our aim is to ensure that all affected children receive optimum care.

Should you have any questions regarding newborn screening in Hesse, your paediatrician, midwife, the medical staff in the hospital where you gave birth, and of course those of us who work at the Hesse Screening Centre, will be happy to provide you with the necessary information. You are also welcome to visit our Internet website at www.screening-hessen.de.

We wish you and your child all the best - and hope our work goes some way towards helping you!

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Hessisches Kindervorsorgezentrum
Screening-Zentrum Hessen
am Universitätsklinikum Frankfurt
Theodor-Stern-Kai 7
60590 Frankfurt/Main
Tel.: 069/6301-80199
Fax.: 069/6301-4643
Email: neugeborenscreening@kgu.de
Web: www.screening-hessen.de
Dear Parents,
most children are born into this world healthy - and remain so. A few rare congenital diseases which affect the metabolism and hormones, however, do exist, that are impossible to detect visually in newborns. If left undetected and untreated, these metabolic and hormonal disorders may lead to organ damage, physical or mental disability. To ensure the prompt detection of these diseases, the newborn screening programme is offered for all newborns. In cooperation with your family physician, we have issued this parents’ leaflet to inform you about the aims and content of the newborn screening programme.
We hope this leaflet provides answers to all your questions. For more information on the various target diseases please visit our website.

Why is such early screening offered and carried out?
Prompt treatment begun as soon as possible after birth may alleviate or even prevent the consequences of rare congenital disorders that affect the metabolism, hormone production, and organ function.

That’s why Hesse has been running and constantly improving its newborn screening programme aimed at the early detection and treatment of metabolic and hormonal disorders for over 40 years.

Please ensure to provide a telephone number and address where you can be reached during the first few days after birth.
The success of screening and prompt treatment in affected newborns depends on all those involved – parents, hospital and/or paediatrician and the Hesse Screening Centre - cooperating with a minimum of lost time. Only then can any findings be established and monitored promptly.

When, how, and where does screening take place?
If written consent is given by the parents, a few drops of blood are extracted from the child’s heel or vein between 36 and 48 hours following the birth; these are dripped onto a filter paper. Once the blood has dried, the sample is sent to the Hesse Screening Centre at the Hesse Paediatric Care Centre. At the Hesse Screening Centre all samples are immediately subjected to specialised and highly sensitive tests.
Should you leave the hospital with your child before 36 hours have expired, we urgently recommend your consent to an early blood sample. A second sample should be taken after 36-72 hours of life.

Who will receive the test results?
Within a few days, the screening results and/or any findings are issued to the submitting institution/individual in writing by the Hesse Screening Centre. In urgent cases, you will be contacted directly and without delay. Please ensure to provide a telephone number and address where you can be reached during the first few days after birth.
The success of screening and prompt treatment in affected newborns depends on all those involved – parents, hospital and/or paediatrician and the Hesse Screening Centre - cooperating with a minimum of lost time. Only then can any findings be established and monitored promptly.

What does the test result mean?
A screening test result does not constitute a medical diagnosis. The test result either allows those diseases under examination to be largely ruled out, or it may indicate a need for further testing in cases where a disease is suspected, e.g. by means of another blood sample.

If the first blood sample was taken less than 36 hours after the birth of your child, a second blood sample should be taken between 36 and 72 hours. A sample taken before 36 hours have expired allows the majority of the target diseases to be recognised; however others can only be detected by a second sample during the time period mentioned above.

Is it possible to heal the diseases detected?
It is not possible to heal all the metabolic and hormonal disorders included in the screening programme. Nevertheless, prompt treatment may help to prevent or at least alleviate the associated negative health effects. Depending on the disease, treatment can take the form of a special diet and/or the administration of medicine.

A comprehensive network of medical practitioners specialising in metabolic and hormonal diseases are at your disposal to provide advice and support in suspected or confirmed cases of illness.

Screening scope, consent and costs
Strictly speaking, the Newborn Screening Programme is not a genetic testing programme. Owing to its “mass screening” nature, however, it is subject to the terms of the German Genetic Diagnostics Act (GenDG).
Pursuant to § 9 para. 1, the GenDG specifies that you as parents are informed about the aim and scope of this programme prior to giving your written consent. Participation in the Hesse Newborn Screening Programme is voluntary. By giving your consent, you make one of these rare congenital disorders in your child very unlikely.
Test results are subject to patient confidentiality and may not be released to third parties without your consent.
This screening programme is free of charge for all children covered by state medical insurance. The parents of children covered by private medical insurance will be billed accordingly.
You decide whether your child should take part in either the standard or extended Hesse Screening programme.

(A) Standard Programme
Sixteen target diseases make up the standard programme (see our website for disease descriptions: www.screening-hessen.de).

Data and remaining blood samples:
This screening programme will store your child’s findings and data for ten years in pseudonymous form pursuant to §12 of the German Genetic Diagnostics Act. Any remaining blood samples will be irrevocably destroyed after a period of six months.