CHARITÉ

CharitéCentrum für Frauen-, Kinder- und Jugendmedizin mit Perinatalzentrum und Humangenetik

Charité | Campus Virchow-Klinikum | 13344 Berlin **Institut für Medizinische Genetik und Humangenetik**

INFORMED CONSENT FOR DNA TESTING

PATIENT NAME:

DATE OF BIRTH:

I authorize the Molecular Genetics Laboratory at Charité University Hospital Berlin to analyze a sample of my/my child's DNA for genetic testing for:

Mabry Syndrome / Hyperphosphatasia with Mental Retardation Syndrome or GPI-anchor deficiency

The results of this test may be used to:

- Diagnose my/my child's medical symptoms.
- Determine my/my child's risk of developing a disease in the future.
- Determine my/my child's chance of passing on a genetic disease (carrier status).

The accuracy of genetic testing depends on the type of test ordered, the nature of the condition, and the accuracy of the clinical information provided. No laboratory test, including DNA testing, is 100% accurate. Given the limitations in current technology, it is possible that the test will not work properly or that a diagnostic error may occur. It is my responsibility to discuss with my physician the limitations of the testing that I am requesting.
In general:

- If the test detects an abnormality in the DNA, the test is >99% accurate.
- Rarely, an abnormality is found for which the clinical significance is not known.
- In other cases, the test is unable to identify an abnormality although the abnormality may still exist. This event may be due to our current lack of knowledge of the complete gene structure or an inability of the current technology to identify certain types of abnormalities in the gene. As a result, a normal test result must be interpreted within the limitations of the specific test.
- The test may reveal previously unrecognized biological relationships, such as nonpaternity. DNA tests also may reveal a genetic condition in another family member.

Test results are confidential:

- Test results will be released to the referring physician or other health care provider as specified on the test requisition.
- Test results will not be released to other individuals without my written consent.
- Test results may be part of my/ my child's medical record and thus accessible to my health insurance provider or other parties within legal limits.

After testing is complete:

- Any remaining sample will be stored in the Laboratory for two (2) years, after which time the sample may be discarded.

The test and its limitations have been satisfactorily described to me. I acknowledge that I have discussed the benefits, risks and limitations of this genetic test with my physician and/or other health care professional. I understand some genetic tests can involve possible medical, psychological or insurance issues for my family and me. I consent to genetic testing as described above. I will receive a copy of this consent form for my records.

Signature: _____
(Patient or Parent)

Witnessed by: _____

Date: _____

Physician's/Genetic Counselor's statement: I have explained DNA testing to this individual. I have addressed the limitations of the test and have answered all stated questions.

Signature: _____