

DNA BANK INFORMATION AND CONSENT

DNA diagnostic studies are available for a number of inherited conditions, providing families with the option of tracking the gene mutation(s) within their family or testing in future pregnancies. Despite these advances there are many genetic conditions for which DNA analysis is not currently available, but may become available in the future.

One unique aspect of DNA analysis is that sometimes DNA samples from affected family members must be compared to those from unaffected members. For some families, death of a family member with a genetic condition makes DNA analysis impossible. In order to store DNA samples from family members so that future diagnostic studies can be performed, a DNA Bank has been established at Seattle Children's. DNA that is stored will be kept in the bank for a minimum of ten years. The DNA Bank will only store the DNA, not analyze or test it; hence results will not be available until DNA analysis is requested. Individuals wishing to store DNA must consent to donate their sample to Seattle Children's as a restricted gift to be used for the sole purpose of genetic testing, diagnosis, and counseling of their family. The sample will not be used for research or commercial purposes unless the donor or legal representative specifically requests release for these purposes.

The use of DNA banking should be discussed with your genetic counselor or geneticist. They can help you decide if and when DNA banking should be considered and from whom blood samples should be obtained. Naturally, DNA storage does not imply that a test is currently available or that a family member has decided to undergo a test.

There is a possibility that DNA samples may be lost in transit or will be inadequate for a future test, due to unforeseen power failures, equipment failures, floods, or other circumstances. It is also important to know that a DNA sample is not permanent. If used for one study it may be depleted so that sufficient DNA might not be available for additional studies. Neither the Hospital nor the DNA Bank ("the Hospital") is liable for damage to or loss of a DNA sample. The Hospital has no fiduciary duty to the donor, family, or heirs, successors, or assigns, other than using the sample for its designated purpose and refraining from using the sample for research or commercial purposes. The Hospital has no duty to account to the donor or any family members, heir, successor, or assign, or to guardians, attorneys-in-fact, or trustees.

Families should maintain close contact with their referring Genetics Clinic to keep updated regarding new developments in DNA testing.

Questions regarding how to release banked DNA to another laboratory should be directed to Lab Client Services at 206-987-2617.

A signed "DNA Bank Restricted Consent" or a "Consent for DNA Retrieval and Use" form must be received by the DNA Bank before DNA will be released to another laboratory.

A copy of this page and the DNA Bank Restricted Consent Form should be provided to the patient/legal representative for their records.

DNA BANK RESTRICTED CONSENT FORM

I hereby consent to the removal of a blood sample for the purpose of obtaining a DNA sample for storage at the Seattle Children's DNA Bank.

I understand that the sample will be used for the sole purpose of genetic testing, diagnosis, and counseling for me or my family members and will not be used for research or commercial purposes unless the donor or legal representative specifically requests release for these purposes.

I hereby donate all right, title, and interest in and to such DNA sample and the products thereof, which I or any family member, descendant, heir, successor, or assign have or may have as to such sample. This does not exclude use of this DNA by my family members in the future for genetic testing.

I have reviewed the DNA Bank information form and understand and agree to its contents.

(Donor/Patient's name)

(Date of Birth)

(Seattle Children's Medical Record #, if available)

(Signature of Patient/Legal Representative)

(Printed Name)

(Relationship to Patient)

(Date)

(Time)

Send the signed consent form to: LabDNABank@seattlechildrens.org or the Molecular Genetics Laboratory fax (206)987-1465; or include signed consent form with blood sample.

Questions regarding sample submission, release of banked DNA, and billing should be directed to Lab Client Services at 206-987-2617.

DO NOT FILE IN PATIENT CHART – CONSENT MUST BE SENT TO MOLECULAR GENETICS LAB