



## **USIDNet DNA / Cell Repository Informed Consent (parent)**

I hereby consent to the collection of \_\_\_\_ml (\_\_\_\_tsp) blood or a tissue biopsy from my child for submission to the **USIDNet DNA and Cell Repository**, a research resource supported by the National Institutes of Health. The Repository collects, stores, and distributes cell cultures and DNA samples from people with all forms of primary immunodeficiency disorder, from unaffected family members and from other healthy people. The samples in the Repository will be maintained by and at Coriell Cell Repositories in Camden, NJ.

I understand that my child's sample will be used to create cell lines that will be added to the Repository's collection. The purpose of this collection is to make specimens readily available for use in research and teaching. Since the Primary Immunodeficiency (PI) diseases are rare, donation of this sample to the Repository may give a broader group of scientists access to rare research materials from patients and families affected with Primary Immunodeficiency. It is hoped that wider scientific access and study may help to improve understanding of these diseases and to develop new diagnostic tests and new treatments for these and other disorders.

The Repository will take strong measures to protect my family's privacy. All identifying information will be removed from the blood or tissue specimen by our doctor before the sample is submitted to the Repository. The specimen will be given a unique code number for future identification and the record maintained by the Repository will only contain general information such as age, sex, state of residence, diagnosis and molecular defect (if known). The USIDNet Repository will not have my child's name, address or other specific identifying information to link the sample specifically to him/her and therefore it is very unlikely that anyone would be able to determine in the future that the sample was taken from my child.

Because the link to our name has been broken, the USIDNet Repository will probably be unable to provide us with any information about scientific findings that may be discovered by scientists working with the sample specifically or whether any results that are published in the scientific literature are related to the sample that we submitted. I understand that a potential link may remain between the sample and my child if the USIDNet Repository keeps a record of the name and address of the physician who submitted this sample. In this event the USIDNet Repository could contact our doctor and potentially transmit back to us study results or a request for my child to participate

in additional studies – although the Repository would still not have our identity in its records and would not have enough information to contact us without the assistance of my doctor. If my doctor is unavailable or is unable to contact us for some reason, I understand that the Repository will not be able to contact us nor provide any information to us concerning my child’s sample.

*I would ( ) would not ( ) like to have my doctor’s name remain linked to my coded sample in the Repository’s records.*

*I would ( ) would not ( ) like to be contacted by my doctor in the future about the results of research studies performed on my sample or with possible opportunities for me to join additional research studies.*

There will be no direct benefit or payment to my child for participating, but the sample may benefit the community at large or some particular group. My child’s sample will stay in the Repository indefinitely and it will not be possible to request its removal from the collection once all information identifying it as coming from my child has been removed.

The medical risks of providing these specimens are minimal. The risk for venipuncture is minor transient pain and slight possibility of infection. The risk for skin biopsy is mild local pain, slight bleeding, the possibility of a small scar, and slight possibility of infection.

This donation is voluntary, and if I choose not to have my child participate there will be no penalty or loss of entitled benefits.

(Signature) \_\_\_\_\_

(Relationship) \_\_\_\_\_ (Date) \_\_\_\_\_

(Submitter) \_\_\_\_\_

(Submitter Address) \_\_\_\_\_

If I have any questions or complications relating to collection of this specimen, I should contact (name) \_\_\_\_\_ (phone) \_\_\_\_\_, who collected the specimen.

If I have any questions about the Repository, I should contact Dr. Christine Beiswanger, Coriell Institute for Medical Research, 403 Haddon Avenue, Camden, New Jersey 08103. (Telephone: 800-752-3805).

If I have questions about my child’s rights as a research subject I should call \_\_\_\_\_ (representative of submitter's IRB)

**To contact the CORIELL CELL REPOSITORIES:**

**Write:** 403 Haddon Avenue; Camden, New Jersey 08103; USA  
**Call:** 800-752-3805 in the United States; 856-757-4848 from other countries  
**Fax:** 856-757-9737  
**e-mail:** [ccr@coriell.org](mailto:ccr@coriell.org)

This consent document was approved for use by the Coriell Institutional Review Board on May 20, 2004.