UGANDA CANCER INSTITUTE RESEARCH AND ETHICS COMMITTEE

SAMPLE STORAGE CONSENT TEMPLATE:

The following should be entailed in the sample storage consent:

1. **Purpose of sample storage:**
   (i) Why store the samples?
   (ii) How much sample would you need to store?
   (iii) Is it the excess from that drawn for primary study purpose or you have intension of obtaining another sample for this purpose?
2. **Procedure:**
   (i) How are will the samples be stored?
   (ii) Where will the samples be stored?
   (iii) How will participant confidentiality be secured? (e.g only PTIDs / Lab access numbers in would be used no participant name).
   (iv) Who are the people that would you would permit access to the stored samples and their affiliation to primary study.
   (v) what are the possible studies that to be done on the stored samples in future
   (vi) Include information in regard to the funding institution policies on sample storage – eg NIH genetic testing on stored samples is a must so participant must be informed that genetic testing would be done in future and how confidentiality for such sensitive information would be kept.
3. **Risks:**

   What are the risks associated with sample storage, gene testing and obtaining an extra sample if it's a requirement for storage?

   How would the risks be minimized?
4. **Benefits:**

   What are the benefits to the participant / and or to the community, or health providers?

Note: researcher may also include any other information deemed relevant to the participant

5. **Statement of voluntariness:**

State that participant in to accept sample storage or decline and this would not affect the participation in the study. Participants also has a right to withdraw consent for sample storage any time , how such

decision would affect the continued study participation and what participant should do in case develops intention to do so.

1. **Contacts for concerns/Questions:**

State how participants who have questions/concerns related sample storage can reach investigators to answer such questions. Explain how participants who have questions about their rights as research participants can have their queries addressed by REC or CAB.

2. **Statement of Consent**

The acknowledging statement that the information in the consent form has been read and explained to the subject, he /she understands, the purpose of sample storage, what is going to be done (procedures) keeping confidentiality, the risks, the benefits involved and the fact that its voluntary; even if he /she declines storage can participate in the study and he/she has voluntarily indicated her option in this regard in the Check boxes below :**(check boxes/Space should be included for participant to indicate her decision)**

A statement that a copy of this form will be provided to the subject

☐ **I agree –to Sample storage** ☐ **I disagree– to Sample storage**

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Name of participant (Print) Signature Date

Note: Only Applicable if NIH funded or depending on the policies of the sponsor and future plan for sample storage involves gene testing

☐ **I agree –to Gene testing** ☐ **I Disagree– to gene testing**

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Name of participant (Print) Signature Date

For consents obtained for child participation:

☐ I agree –to Sample storage ☐ I disagree– to Sample storage

Name of child (Print)

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Name of caretaker (Print) Signature Date

☐ I Agree –to child gene testing ☐ I disagree – to child gene testing

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Name of caretaker (Print) Signature Date

Note: Only Applicable if NIH funded or depending on the policies of the sponsor and future plan for sample storage involves gene testing

Caretakers' relationship with the child ----------

Witness:

Statement that I attest that the information in this document was read to the participant /caretaker and she /he understands the purpose of the sample storage, what is going to be done (procedures) confidentiality will be kept, the risks, the benefits involved and his /her rights regarding consent for sample storage .He /she voluntarily consented for his/her (child's) samples to be stored for future use

To those that used thumb print for consent (Only):

a) **Individual participants:**

I attest that the participants' name is----------
– has placed a his/her thumbprint on this consent form on this date----------

b) Caretakers:

I attest that the caretakers name is ---------- and has placed his/her thumbprint on this consent form to allow the samples for the child called ---------- to be stored for future use on this date----------

Caretakers' relationship with the child ----------

Note: For children investigator could include line for another person that could sign for Child's sample storage e.g In incidences where father and mother are present at a session or another relative that has consented for child's study participation may consent also for sample storage.

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Name of witness (Print) Signature Date

(To consent process)

Note: Be specific if witness is not necessary during consenting of all participants eg witness to consent process for those using thumbprint only.

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Name of study staff Signature Date

Obtaining consent (Print)

Note: Include version and date for easy tracking of consent revisions (especially for studies with long follow –up periods).