MAKERERE UNIVERSITY

COLLEGE OF VETERINARY MEDICINE, ANIMAL RESOURCES & BIOSECURITY

P.O. Box 7062 Kampala, Uganda
Fax: +256-414-554685/534336
Email: sbls@covab.mak.ac.ug

SCHOOL OF BIOSECURITY, BIOTECHNICAL AND LABORATORY SCIENCES

Sample Storage Consent for Study Participants

I. INFORMATION SHEET (Bilharzia Study)

Study Name: TrypanoGEN^{+}: the Genetic Determinants of two Neglected Tropical Diseases

Principal Investigator: Dr. Enock Matovu, College of Veterinary Medicine, Animal Resources and Biosecurity, Makerere University, P. O. Box 7062 Kampala, Uganda, Email: matovue@covab.mak.ac.ug, Tel. +256 414-533002

General information
This informed consent document is divided into two parts: The first is the information sheet to enable sharing the facts about the research with you, and the second is the certificate of consent for signatures and/or thumb prints if you agree to participate.

Part I: Information sheet
Introduction
I am ..... a Doctor/Clinical Officer at .... We have invited your child/dependant to participate in a study whose aim is to investigate the natural causes of differential susceptibility to Bilharzia, and you have dully accepted to participate.
Your child/dependant's participation is voluntary. Before agreeing to this part of the study, we request you to read this form, or we will go through it with you.

Purpose
As already explained to you, the sample that your child/dependant is about to provide will be used to study Bilharzia susceptibility in different individuals. About 2000 volunteers will participate in this study. In order to facilitate future research, we would like to store any remaining sample in a specimen collection at Makerere University, for future use in genetic studies. In this consent document therefore, we would like to request you for permission to store your child/dependant's sample for this purpose. If you agree to this request, the samples will be stored at the College of Veterinary Medicine, Makerere University. An aliquot the same sample may also be stored at the biorepository at the Makerere University College of Health Sciences (Medical School, Mulago). The sample will be stored for a period of 5 years or more, whichever you are going to decide below. Thereafter the sample will be burnt in an incinerator as is usually done with biological waste from a laboratory.

Risks/discomforts
There is no health risk to you or your child/dependant from storage of the sample. Our team will ensure protection of that sample from misuse for purposes outside genetic studies.

Benefits
By allowing long term storage of your child/dependant's sample, you provide the opportunity to gain more understanding of human susceptibility to disease leading to better control or even to eliminate

VECTOR CONTROL DIVISION (MoH)
APPROVED
VALID UNTIL
31 DEC 2020
RESEARCH & ETHICS COMMITTEE
P. O. BOX 1661, KAMPALA

it from your area. Participation will therefore go a long way towards reducing the suffering and death of our populations from Bilharzia.

Confidentiality
Your child/dependant's identity and participation in this study will be strictly confidential. Names will not appear with the information pertaining to results of our tests. Only authorized medical staff will have access to information bearing your child/dependant's name.

Right to refuse or withdraw consent
You have the right to choose whether or not to allow long-term storage of your child/dependant's sample, or to withdraw that consent as well as the sample at a later date. This will not affect your or dependant's rights to access to healthcare or other benefits from any public facility.

Questions related to this study
You have the right to ask any questions you may have about this study. If you have any further question or you want to withdraw from the study, you can contact Dr. Matovu (Tel: 0772550226), or any member of the study team, at any time. This study was approved by the Vector control Division's research and ethics committee, accredited by the Uganda national Council for Science and Technology (UNCST). If you have questions regarding your rights, please contact the chairman of that committee, Dr. Abbas Kakembo (Tel: 0771828378).

Part II: Participant (or Guardian) consent for storage of samples for future use
By signing this section I confirm that I have voluntarily agreed to long term storage of my child/dependant's sample for future use while investigating the genetic basis for susceptibility to disease. These samples may be stored for the period and condition below (Please select by writing "Yes" to one of the options below and "No" to the rest).

a. Five years to study human susceptibility to Bilharzia only :.....
b. Five years to study human susceptibility to any disease :.....
c. For as long as it is still available, to study susceptibility to Bilharzia only :.....
d. For as long as it is still available, to study human susceptibility to any disease :.....

Name of Participant.....

Name of Parent/Guardian.....

Signature/thumb print ..... Date ...../...../20....

There should be a witness f the parent/guardian is unable to read or write

I have witnessed the consent process for this participant/guardian, who had ample opportunity to ask questions. I confirm that the participant/guardian has freely given consent.

Name of Witness.....

Signature..... Date ...../...../20....

I have accurately read or witnessed the accurate reading of the consent form to the parent/guardian, and the individual had ample opportunity to ask questions. I confirm that the parent/guardian has freely given consent for sample storage. A copy of this informed consent has been provided to the participant

Name of Researcher.....

Signature..... Date ...../...../20....