Appendix: 3

Informed Consent Form

- Confirm that I have read the written information (or have had the information read to me) for study “Role of Biomarkers CCL18/PARC and Heparin – Thrombin II cofactor for diagnosis and monitoring of Lysosomal Storage Disorders in Indian children” and the study procedures have been explained to me by study staff during the consent process for this study.

- Confirm that I have had the opportunity to ask questions about this study and I am satisfied with the answers and explanations that have been provided.

- Understand that I grant access to data to authorized persons described in the information sheet.

- Have been given time and opportunity to consider allowing my child/ward to participate in this study.

- Understand that my child’s/ward’s participation in the study is voluntary and that I am free to withdraw him/her at any time, without giving any reason, without my medical care or legal rights being affected.

- The Institutional Ethics Committee will not need my permission to look at my child’s/ward’s health records both in respect of the current study and any further research that may be conducted in relation to it, even if I that my child’s/ward’s identity will not be revealed in any information released to third parties or published.
Tick as appropriate (this decision will not affect your ability to enter the study):

I agree that my child’s/ward’s biological samples may be used for further research that is not related to the disease under study. This will be done on an anonymous basis (meaning that any identification linking my child/ward to the sample is destroyed). I understand that if I select “No”, it will not affect my child’s/ward’s participation in the study.

Yes       No

I agree to allow my child/ward to take part in this study

Signature of Legal ________________________ Date: ____________

Representative/Name ________________________ Date: ____________

If applicable ________________________ Date: ____________

Signature of Witness /Name ________________________ Date: ____________

Signature of Person ________________________ Date: ____________

Conducting consent/Name ________________________ Date: ____________