APPENDICES

Appendix A Covering Page to Patient Questionnaire

CHECK LIST FOR HIV POSITIVE WOMEN OF ADVANCED MATERNAL AGE

Date of Interview: ……...……

Hospital: ……...…

Hospital number: ……....

Patient Name: ……....

Patient code: …….

To be detached and filed separately by Researcher to maintain confidentiality

Appendix B: Patient Information

Patient Information Check List

Patient code: .....… Date: …….

Date of Birth: ……..… Age: …….

Para: ……

Gravida: ……

Marital status: Married □ In relationship □

Single □ Divorced □

Patient's occupation: ……..

Partner's occupation: ……..

Gestation:

On LMP: ……

On Sonar: …… Date of sonar examination: ……

Patient Check List

1. Was this a planned pregnancy? YES □ NO □
2. Did the doctor or person at the clinic inform the patient about her increased risk of having a baby with an abnormality because of her AMA?

   YES □ NO □
3. Has the patient been tested for HIV during or prior to this pregnancy?

   YES □ NO □
4. If yes, when? Date:.....
5. What was the result of the HIV test?

   HIV positive □ HIV negative □ Result not known □

   Awaiting result □ When will she get the result?.....

   Test refused □ Reason for refusal .....
6. If positive, has patient informed her partner about her result?

   YES □ NO □ Planning to tell him □
7. If yes, has partner been tested for HIV?

   YES □ NO □ Intends to go for testing □

8. In patients who are HIV positive, what advice was the patient given by her HIV counsellor about the future health and care of the baby?

   Advised nothing □

   Advised about risk of baby becoming HIV positive □

   Advised on option of TOP (If patient less than 20 weeks gestation) □

   Advised on options to reduce transmission risks:

   ART (Nevirapine) □

   Avoidance of breast feeding □

   Other advice given:.....……

   ……..

9. What did the patient understand were the risks of her baby becoming HIV positive (with and without perinatal nevirapine prophylaxis)?

.....

10. Was the patient aware that HIV is a fatal disease? ……

11. Did the patient want TOP based on the risk of HIV transmission?

    YES □ NO □ Comment: …….

    …….

12. Would the patient have requested amniocentesis if she was:

AMA only	YES □	NO □
AMA and HIV positive status (no ART)	YES □	NO □
AMA, HIV positive status and free ART cover	YES □	NO □
AMA, HIV positive status, purchased ART cover	YES □	NO □

    Comment:……

13. Other factors influencing the patient's decision regarding amniocentesis: ……

14. Did patient have amniocentesis?

    YES □ NO □ TO DECIDE □

Appendix C: Consent Form

LETTER OF INTRODUCTION AND CONSENT FORM

Project Title: The influence of HIV on women of advanced maternal age presenting for Genetic Counselling.

Researcher: Justine Bee, BSc Hons(Genetics)
Department of Human Genetics, University of the Witwatersrand

Supervisor: Professor AL Christianson
Department of Human Genetics, National Health Laboratory Service
University of the Witwatersrand (011) 489 9223

I am ..... (Counsellor/Clinician's name) and I am part of the Genetic Counselling Clinic, of the Division of Human Genetics of the National Health Laboratory Services (NHLS), School of Pathology, University of the Witwatersrand. We are conducting a study to find out how HIV infection affects the decisions pregnant women of advanced maternal age (AMA) have to make. Women of AMA are those who are pregnant when they are over 35 years old.

Pregnant women of 35 years and older are referred to this clinic, where their chances of having a baby with a chromosomal abnormality, such as Down syndrome, are discussed with them. A test, called amniocentesis, is offered to these women. This is done between 16 and 23 weeks pregnancy. The babies of HIV positive pregnant women are thought to be at risk of getting HIV during the amniocentesis. This is because the test involves a needle going through the woman's abdomen and into the fluid around the baby.

I would like to use information obtained during your genetic counselling session for research purposes. We wish to use this to get a better understanding of the difficulties facing women of AMA who are HIV positive. If you give consent for information to be used it is with the understanding that this information will remain confidential. You will be given a code number so that your name does not appear anywhere on the information sheet. The information from a number of patients will be analysed and be used to improve the genetic counselling services we offer at this and other hospitals.

A genetic counselling session takes between 45 minutes to an hour. Agreeing to be part of this study will add about 15 minutes to the session time.

Regardless of if you give consent or not, you will not be treated differently in any way. If you consent to information from your counselling session being used in the study, please sign below.

I,.....(full name) give permission to the researcher to use information from my face sheet in a study investigating the impact of HIV/AIDS on the genetic counselling sessions of pregnant women of advanced maternal age. I understand that the information will remain confidential, and is for research purposes.

Signature: .....

Date: .....

Phone number: ..... Patient code: .....

Appendix D: Ethics Approval

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Bee

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER 03-06-05**
PROJECT	The Influence of HIV Status on Women of Advanced Maternal Age Presenting fior Genetic Counseling
INVESTIGATORS	Ms J Bee
DEPARTMENT	School of Pathology
DATE CONSIDERED	03-06-27
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 04-01-29 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof AL Christianson
School of Pathology

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

This ethical clearance will expire on 1 February 2008
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES