

Section A: KEY IDENTIFYING INFORMATION

- A1. Study Identification Number _____ - _____ - _____ - _____
- A2. Study visit GENETICS VISIT.....77
- A3. Date interview conducted _____ / _____ / _____
M M / D D / Y Y Y Y
- A4. Person providing the history MOTHER1 **(A5)**
FATHER2 **(A5)**
OTHER..... 3
a. SPECIFY: _____
- A5. Date form completed _____ / _____ / _____
M M / D D / Y Y Y Y
- A6. Name of person completing form _____
PRINT FULL NAME INITIALS

Section B: PRENATAL HISTORY

- B1. What is your (the mother's) date of birth? _____ / _____ / _____
M M / D D / Y Y Y Y
- B2. What is the father's (your) date of birth? _____ / _____ / _____
M M / D D / Y Y Y Y

Please tell me more about your (the mother's) pregnancy with the child taking part in this study.

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	YES	NO	DK	†SC
B3. Are you (the mother) and the father (you) blood-related to each other? (HISTORY OF CONSANGUINITY)	1	2	-8	
B4. Did you (the mother) have an amniocentesis ¹ during this pregnancy?	1	2 (B5)	-8 (B5)	
a. Were the results normal?	1 (B5)	2	-8 (B5)	
b. IF NO: Please tell me what the results were.				
SPECIFY: _____				
B5. Did you (the mother) have serum screening ² done?	1	2 (B6)	-8 (B6)	
a. Were the results normal?	1 (B6)	2	-8 (B6)	
b. IF NO: Please tell me what the results were.				
SPECIFY: _____				
B6. Did you (the mother) have a fetal ultrasound ³ performed during this pregnancy?	1	2 (B7)	-8 (B7)	
a. Were the results normal?	1 (B7)	2	-8 (B7)	
b. IF NO: Please tell me what the results were.				
SPECIFY: _____				

¹ AMNIOCENTESIS = TRANS-ABDOMINAL PERFORATION OF THE AMNIOTIC SAC TO OBTAIN AN AMNIOTIC FLUID SAMPLE

PARENT EXPLANATION: Amniocentesis is a procedure some mothers might have to check for certain genetic and congenital abnormalities before the baby is born. It involves placing a needle through the mother's abdomen to take a small amount of amniotic fluid. Did you (Did the mother) have this procedure done during this pregnancy?

² SERUM SCREENING = BLOOD TEST MEASURES MATERNAL α-FETOPROTEIN LEVELS; SCREENS FOR NEURAL TUBE DEFECTS, TRISOMY 18 & TRISOMY 21 (DONE IN 2ND TRIMESTER)

PARENT EXPLANATION: During the 2nd trimester, some mothers may have a blood test, called serum screening, to check for proteins in the blood that may mean their baby has spina bifida, Downs syndrome, or a rare condition called Trisomy 18. Did you (Did the mother) have this test done during this pregnancy?

³ ULTRASOUND = USES HIGH FREQUENCY SOUND WAVES TO VISUALIZE DEEP BODY STRUCTURES

PARENT EXPLANATION: A fetal ultrasound is a way to see deep inside the abdomen, and is used to record a picture of the baby before it's born. Ultrasounds can check the baby's size & health. Did you (Did the mother) have this test done during this pregnancy?

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B7. Please tell me if you (the mother) were (was) exposed to any of the following during the first 3 months of this pregnancy⁴:

	YES	NO	DK	†SC
a. Cigarette smoke (primary <u>or</u> second hand smoke)	1	2	-8	
b. Alcohol	1	2	-8	
c. Cocaine	1	2	-8	
d. Heroin	1	2	-8	
e. Marijuana (primary <u>or</u> second hand smoke)	1	2	-8	
f. General anesthesia	1	2	-8	
g. Prescription medications	1	2 (B8)	-8 (B8)	

i. IF YES: How many medications: ____ (1-5)

Please tell me the names of the medications you (the mother) were taking.

ii. MEDICATION NAMES	ENTER CODE FROM PHN CODE LIST D
1. _____	i. _____ . _____
2. _____	i. _____ . _____
3. _____	i. _____ . _____
4. _____	i. _____ . _____
5. _____	i. _____ . _____

IF MORE THAN FIVE MEDICATIONS, PLEASE PHOTOCOPY THIS PAGE AS NEEDED.

⁴ PARENT EXPLANATION: The first three months of a pregnancy are when many of the baby's major organs, like the brain & heart, begin to develop. If a mother is exposed to certain substances during this time, it can affect the way the baby grows. We are asking all parents who take part in this study to tell us if their child may have been exposed to certain substances before they were born. This will help us learn more about what things may or may not affect children's development. You can choose not to answer any question that makes you feel uncomfortable.

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B8. Were any of the following present during your (her) pregnancy?

	YES	NO	DK	↑SC
a. Too much amniotic fluid ⁵	1 (B8c)	2	-8	
b. Not enough amniotic fluid ⁵	1	2	-8	
c. High blood pressure (diagnosed during pregnancy)	1	2	-8	
d. Diabetes (present before pregnancy)	1 (B8f)	2	-8	
e. New diagnosis of diabetes (GESTATIONAL DIABETES)	1	2	-8	
f. German measles (RUBELLA)	1	2 (B9)	-8 (B9)	

i. IF YES: In which trimester of your (the mother's) pregnancy did you (she) first have German measles (rubella)?
(SELECT ONLY ONE OF THE FOLLOWING ANSWERS)

FIRST TRIMESTER.....1
SECOND TRIMESTER.....2
THIRD TRIMESTER.....3

B9. Did any of the following conditions occur during your (her) pregnancy?

a. Fever > 102°F

	YES	NO	DK	↑SC
	1	2 (B9b)	-8 (B9b)	
IF YES: In which trimester(s)?				

i.	FIRST TRIMESTER	1	2	-8	
ii.	SECOND TRIMESTER	1	2	-8	
iii.	THIRD TRIMESTER	1	2	-8	

⁵ AMNIOTIC FLUID = ALBUMINOUS FLUID CONTAINED IN THE AMNIOTIC SAC. EXCESSIVE AMOUNTS (POLYHYDRAMNIOS) FREQUENTLY OCCUR WITH MULTIPLE PREGNANCIES OR SOME CONGENITAL DEFECTS. SMALL AMOUNTS (OLIGOHYDRAMNIOS) MAY RESULT IN PRESSURE DEFORMITIES OR ADHESIONS.

PARENT EXPLANATION: Amniotic fluid is the liquid that surrounds the baby inside the mother's uterus. This liquid cushions the baby and provides it with fluids. Having too much or too little fluid can affect the health of the baby. Were you (Was the mother) told that you (she) had too much or not enough amniotic fluid during your (her) pregnancy?

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B9.	Did any of the following conditions occur during your (her) pregnancy?	YES	NO	DK	†SC
	b. Bladder infection (or UTI)	1	2 (B10)	-8 (B10)	
	IF YES: In which trimester(s)?				
i.	FIRST TRIMESTER	1	2	-8	
ii.	SECOND TRIMESTER	1	2	-8	
iii.	THIRD TRIMESTER	1	2	-8	

					†SC
B10.	Did you (the mother) have any other infections during your (her) pregnancy?	YES.....	1		
		NO.....	2 (B11)		
		DK.....	-8 (B11)		
a.	How many other infections did you (the mother) have during your (her) pregnancy?	_____	(1-5)		

Please tell me the name(s) of the infection(s) and which trimester of your (her) pregnancy it (they) first occurred in.

		YES	NO	DK	†SC
b.	_____				
i.	FIRST TRIMESTER	1	2	-8	
ii.	SECOND TRIMESTER	1	2	-8	
iii.	THIRD TRIMESTER	1	2	-8	
c.	_____				
i.	FIRST TRIMESTER	1	2	-8	
ii.	SECOND TRIMESTER	1	2	-8	
iii.	THIRD TRIMESTER	1	2	-8	

IF MORE THAN TWO INFECTIONS, PLEASE PHOTOCOPY THIS PAGE AS NEEDED.

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↓

		†SC
B11. Did you (the mother) have any other complications during your (her) pregnancy?	YES..... 1	
	NO..... 2 (C1)	
	DK..... -8 (C1)	
a. How many other complications did you (the mother) have during your (her) pregnancy?	_____ (1-5)	

Please tell me what the complications(s) was (were) and which trimester of your (her) pregnancy it (they) first occurred in.

		YES	NO	DK	†SC
b.	_____				
i.	FIRST TRIMESTER	1	2	-8	
ii.	SECOND TRIMESTER	1	2	-8	
iii.	THIRD TRIMESTER	1	2	-8	
c.	_____				
i.	FIRST TRIMESTER	1	2	-8	
ii.	SECOND TRIMESTER	1	2	-8	
iii.	THIRD TRIMESTER	1	2	-8	

IF MORE THAN TWO COMPLICATIONS, PLEASE PHOTOCOPY THIS PAGE AS NEEDED.

Section C: PAST OBSTETRIC HISTORY

C1. How many pregnancies have you (has the mother) had as of today's date, including the child in this study? _____ (1 – 10)

C2. How many living siblings does the child in this study have in total, including both full and half siblings? _____ (0 – 10)

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		+SC	
C3.	Have you (Has the mother) had any miscarriages? ⁶	YES..... 1	
		NO..... 2 (C4)	
		DK..... -8 (C4)	
	a. IF YES: How many miscarriages have you (has the mother) had?	_____ (1 – 10)	
		+SC	
C4.	Have you (has the mother) ended or terminated any pregnancies? ⁶	YES..... 1	
		NO..... 2 (C6)	
		DK..... -8 (C6)	
	a. IF YES: How many pregnancies were ended or terminated?	_____ (1 – 10)	
		+SC	
C5.	Did you (did the mother) ever terminate a pregnancy due to a known cardiac defect?	YES..... 1	
		NO..... 2 (C6)	
		DK..... -8 (C6)	
	a. IF YES: Please tell me which cardiac defect was present.		
	SPECIFY: _____		
		+SC	
C6.	Have any of the study subject's siblings passed away, including both full and half siblings? ⁶	YES..... 1	
		NO..... 2 (Z1)	
		DK..... -8 (Z1)	
	a. IF YES: How many?	_____ (1 – 10)	

⁶ PARENT EXPLANATION: We are asking all parents who take part in this study about previous miscarriages, elective terminations, and if any of their children have passed away. Sometimes these events happen because a genetic abnormality was present. This information will help us learn more about what factors may or may not relate to children born with cardiac defects. You can choose not to answer any question that makes you feel uncomfortable.

C6.
(cont)

b.

SIBLING #

- i. Was this child a boy or a girl? MALE..... 1
FEMALE..... 2
- ii. Did this child have the same parents as your child participating in the study? YES..... 1 (C6bv)
NO..... 2

HALF SIBLING

- iii. Did this child have the same mother? (MATERNAL HALF SIBLING) YES..... 1 (C6bv)
NO..... 2
- iv. Did this child have the same father? (PATERNAL HALF SIBLING) YES..... 1 (C6bv)
NO..... 2
- v. Did this child have a cardiac problem? YES..... 1
NO..... 2 (C6bvi)
1. What was the cardiac problem? (ENTER CODE FROM CARDIAC CODE LIST)

i. SPECIFY: _____

- vi. What was the cause of death for this child?
SPECIFY: _____

vii. What was the child's date of birth? / /

viii. What was the child's date of death? / /

IF MORE THAN ONE DECEASED SIBLING, PLEASE PHOTOCOPY THIS PAGE AS NEEDED.

Section Z: TIME TO COMPLETE FORM

Z1. How long did it take to complete this form? ___ ___ ___ minutes

END OF SECTION**NOTE:**

- If subject has living siblings, continue to R13Y (Sibling Medical History).
- If no living siblings, continue to R13Z (Family Medical History).