Bench to Bassinet
Pediatric Cardiac Genomics Consortium: CHD GENES
Form 103: Pregnancy and Birth History Interview, Subject <= 1 year
Version: C - 3/16/2011

SECTION A: ADMINISTRATIVE INFORMATION

[**INSTRUCTIONS:** DO NOT READ QUESTIONS IN SECTION A TO RESPONDENT]

A1. Study Identification Number:

A2. Study Visit:

A3. Date Interview Completed: *MM/DD/YYYY*

A4. Interview Language:
- ENGLISH **-> SKIP TO A6**
- SPANISH **-> SKIP TO A5**
- OTHER

a. If Other, please specify:

	Yes	No	N/A - Coordinator fluent	Other
A5. Was a translator used?				

a. If Other, please specify:

A6. Relationship of person interviewed to subject:
(check all that apply)
- a. MOTHER:
- b. FATHER:
- c. LEGAL GUARDIAN:
- d. OTHER:
  - i. IF OTHER, SPECIFY:

SECTION B: SUBJECT'S BIRTH HISTORY

To begin, we have a few questions about your child.

B1. How much did your child weigh at birth?

	pounds/ ounces	kilograms	REFUSED	DON'T KNOW	SOURCE PENDING
a. BIRTH WEIGHT UNIT:					

-> IF KILOGRAMS, SKIP TO B1d;
-> IF REFUSED, DON'T KNOW, OR SOURCE PENDING SKIP TO B2

b. POUNDS: lbs c. OUNCES: oz **-> SKIP TO B2**

d. KILOGRAMS: kgs

B2. What was your child's birth length?

	inches	centimeters	REFUSED	DON'T KNOW	SOURCE PENDING
a. BIRTH LENGTH UNIT:					

-> IF REFUSED, DON'T KNOW, OR SOURCE PENDING SKIP TO B3

b. BIRTH LENGTH:

B3. What was your child's head circumference at birth?

	inches	centimeters	REFUSED	DON'T KNOW	SOURCE PENDING
a. HEAD CIRCUMFERENCE UNIT:					

-> IF REFUSED, DON'T KNOW, OR SOURCE PENDING SKIP TO B4

b. HEAD CIRCUMFERENCE:

B4. What was your child's gestational age at birth? **-> IF REFUSED OR DON'T KNOW SKIP TO B5; IF SOURCE PENDING SKIP TO C1**
- a. WEEKS:
- b. DAYS: **-> SKIP TO C1**

	Yes	No	REFUSED	DON'T KNOW
B5. Was your child born premature?				

SECTION C: INFORMATION ON SUBJECT'S MOTHER

The following questions are about your (the mother's) relationship to the child taking part in this study.

	Yes	No	REFUSED	DON'T KNOW	
C1. Are you the birth mother of the child in this study?	○	○	○	○	**-> IF YES SKIP TO C2**
a. Do you have any information about the birth mother's pregnancy?	○	○	○		

	Yes	No	REFUSED	DON'T KNOW	
C2. Are you the biological mother of the child in this study?	○	○	○	○	**-> IF YES AND C1 OR C1a IS YES, SKIP TO D1; IF YES AND C1 AND C1a IS NOT YES, SKIP TO E1**
a. Do you have any information about the biological mother's pregnancy history?	○	○	○		**-> IF YES AND C1 OR C1a IS YES, SKIP TO D1; IF YES AND C1 AND C1a IS NOT YES, SKIP TO E1**
b. Was your child adopted?	○	○	○	○	

-> IF C1 OR C1a IS YES, ASK D1; OTHERWISE END INTERVIEW

SECTION D: BIRTH MOTHER'S PREGNANCY WITH SUBJECT

The following questions are about the pregnancy of the child taking part in this study.

D1. Was this a single or multiple birth?

- ○ Singleton
- ○ Twins
- ○ Triplets
- ○ Quads
- ○ Quints
- ○ Other
- ○ REFUSED
- ○ DON'T KNOW

a. IF OTHER: Please specify: _____

D2. What was the method of conception?

- ○ Natural **-> SKIP TO D3**
- ○ Adoption **-> SKIP TO D3**
- ○ Assisted Reproductive Technology **-> SKIP TO D2b**
- ○ Other
- ○ REFUSED **-> SKIP TO D3**
- ○ DON'T KNOW **-> SKIP TO D3**

a. IF OTHER: Please specify: _____ **-> SKIP TO D3**

b. What type of Assisted Reproductive Technology was used?

	Yes	No	REFUSED	DON'T KNOW
i. Intrauterine Insemination (IUI)?	○	○	○	○
ii. In vitro fertilization (IVF)?	○	○	○	○
iii. In vitro fertilization (IVF) with intracytoplasmic sperm injection (ICSI)?	○	○	○	○
iv. Donor egg?	○	○	○	○
bv. Donor sperm?	○	○	○	○
vi. Donor embryo?	○	○	○	○
vii. Surrogate?	○	○	○	○
viii. Gestational Carrier?	○	○	○	○

Now we have a few questions about the birth mother's height and weight before this pregnancy.

D3. How tall is the birth mother?

	Feet/inches	Centimeters	REFUSED	DON'T KNOW	SOURCE PENDING	
a. HEIGHT UNIT:	○	○	○	○	○	**-> IF CENTIMETERS, SKIP TO D3d; -> IF REFUSED, DON'T KNOW, OR SOURCE PENDING SKIP TO D4**

b. FEET: _____ ft c. INCHES: _____ in **-> SKIP TO D4**

d. CENTIMETERS: _____ cm

D4. What was the birth mother's weight before she became pregnant with [SUBJECT'S NAME]?

	Pounds	Kilograms	REFUSED	DON'T KNOW	SOURCE PENDING	
a. WEIGHT UNIT:	○	○	○	○	○	**-> IF KILOGRAMS, SKIP TO D4c; -> IF REFUSED, DON'T KNOW, OR SOURCE PENDING SKIP TO D5**

b. POUNDS: ____lbs **-> SKIP TO D5**

c. KILOGRAMS: ____kgs

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

D5. Has the birth mother ever had any of these illnesses or conditions?

	Yes	No	REFUSED	DON'T KNOW	
a. Epilepsy or seizure disorder?	○	○	○	○	**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D5b**
IF YES:	**Yes**	**No**	**REFUSED**	**DON'T KNOW**	
i. Did she have this in the 6 months before the pregnancy with [SUBJECT'S NAME]?	○	○	○	○	
ii. Did she have this during the pregnancy with [SUBJECT'S NAME]?	○	○	○	○	

	Yes	No	REFUSED	DON'T KNOW	
b. Diabetes?	○	○	○	○	**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D5c**

IF YES:	**Type 1**	**Type 2**	**REFUSED**	**DON'T KNOW**
i. What type of diabetes?	○	○	○	○

	Yes	No	REFUSED	DON'T KNOW
ii. Did she have this in the 6 months before the pregnancy with [SUBJECT'S NAME]?	○	○	○	○
iii. Did she have this during the pregnancy with [SUBJECT'S NAME]?	○	○	○	○

	Yes	No	REFUSED	DON'T KNOW	
c. Thyroid Disease?	○	○	○	○	**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D5d**

IF YES: What type of Thyroid Disease?	**Yes**	**No**	**REFUSED**	**DON'T KNOW**
i. Hypothyroidism	○	○	○	○
ii. Hyperthyroidism	○	○	○	○
iii. Other	○	○	○	○

a. IF OTHER: Please specify: ____

	Yes	No	REFUSED	DON'T KNOW
iv. Did she have this in the 6 months before the pregnancy with [SUBJECT'S NAME]?	○	○	○	○
v. Did she have this during the pregnancy with [SUBJECT'S NAME]?	○	○	○	○

	Yes	No	REFUSED	DON'T KNOW	
d. Depression, mood disorder or other psychiatric disorder?	○	○	○	○	**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D5e**
IF YES:	**Yes**	**No**	**REFUSED**	**DON'T KNOW**	
i. Did she have this in the 6 months before the pregnancy with [SUBJECT'S NAME]?	○	○	○	○	
ii. Did she have this during the pregnancy with [SUBJECT'S NAME]?	○	○	○	○	

	Yes	No	REFUSED	DON'T KNOW	
e. Lupus or other autoimmune disease?	○	○	○	○	**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D5f**
IF YES:	**Yes**	**No**	**REFUSED**	**DON'T KNOW**	
i. Did she have this in the 6 months before the pregnancy with [SUBJECT'S NAME]?	○	○	○	○	
ii. Did she have this during the pregnancy with [SUBJECT'S NAME]?	○	○	○	○	

	Yes	No	REFUSED	DON'T KNOW	
f. Other Significant Condition?					**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D6**

i **IF YES:** Please specify

	Yes	No	REFUSED	DON'T KNOW
ii. Did she have this in the 6 months before the pregnancy with [SUBJECT'S NAME]?				
iii. Did she have this during the pregnancy with [SUBJECT'S NAME]?				

D6. Did the birth mother take any of the following vitamins or supplements in the 6 months before she became pregnant with [SUBJECT'S NAME]?

	Yes	No	REFUSED	DON'T KNOW
a. Prenatal vitamins				
b. Multi-vitamins				
c. Supplemental folic acid				

D7. Did the birth mother have any of these illnesses or conditions during her pregnancy with [SUBJECT'S NAME]?

	Yes	No	REFUSED	DON'T KNOW	
a. Gestational Diabetes?					**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D7b**
IF YES:How was it controlled?					
i. Controlled by diet					
ii. Controlled by medication					
b. Sinus infection					
c. High Fever (>100° Fahrenheit)					
d. Toxemia					
e. Pre-eclampsia					
f. Hypertension (or high blood pressure)					

D8. Did the birth mother consume or was she exposed to any of the following during the first 3 months of this pregnancy?

	Yes	No	REFUSED	DON'T KNOW	
a. General Anesthesia (for example, during surgery or a procedure)					
b. Prescription Medications (for example, medications for high blood pressure, blood thinners, mood disorders like depression, seizures, severe acne or oral contraceptives)					**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D8c**

(**PROBES:**Think about medications for high blood pressure, blood thinners, mood disorders like depression, seizures, severe acne, and oral contraceptives. Think about any pills that the birth mother took by mouth, or liquids that she drank. Think about aerosols that she inhaled, patches that she placed on her skin, or medicines she injected with a syringe. Some prescribed medications like aspirin are actually available without a prescription but I will list them here if a doctor or nurse prescribed them.)

i. **MEDICATION NAME (ENTER NAME PRECISELY)**

	Yes	No	REFUSED	DON'T KNOW	
c. Over the Counter Medications (for example, prenatal vitamins, other vitamins or supplements like folic acid)					**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D8d**

(**PROBES:** This includes medication that the birth mother took on her own for any reason, including prenatal vitamins, any other vitamins and supplements, such as folic acid, or medications she may have taken for pain relief or inflammation like ibuprofen, Advil or Motrin or for congested sinuses like sudafed. This also includes any medications that she may have taken on the advice of someone else.)

i. **MEDICATION NAME (ENTER NAME PRECISELY)**

	Yes	No	REFUSED	DON'T KNOW	
d. Alcohol	○	○	○	○	**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D8e**

i. During those 3 months, how many days in an average week did the birth mother drink any kind of alcoholic beverage, including wine, liquor, beer or wine coolers?

ii. When the birth mother drank, how many drinks per day did she consume on average?

iii. What was the greatest number of drinks the birth mother had on any one occasion?

	Yes	No	REFUSED	DON'T KNOW
e. Cocaine	○	○	○	○
f. Heroin	○	○	○	○
g. Crack	○	○	○	○
h. Other Street Drugs	○	○	○	○

i. **IF YES:** Please specify

D9. Smoking History

	Yes	No	REFUSED	DON'T KNOW	
a. Did the birth mother smoke before this pregnancy?	○	○	○	○	
b. Did the birth mother smoke during this pregnancy?	○	○	○	○	**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D9c**
During which trimester(s)?					
i. First	○	○	○	○	
ii. Second	○	○	○	○	
iii. Third	○	○	○	○	

iv. On average, how many cigarettes did the birth mother smoke per day?

	Yes	No	REFUSED	DON'T KNOW	
c. Did the father smoke before this pregnancy?	○	○	○	○	
d. Did the father smoke during this pregnancy?	○	○	○	○	**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO D10**

i. On average, how many cigarettes did the father smoke per day?

D10. Did the birth mother have any of the following prenatal screening tests during this pregnancy?						**IF YES:** Were the test results normal or abnormal?			
	Yes	**No**	**REFUSED**	**DON'T KNOW**	**SOURCE PENDING**	**Normal**	**Abnormal**	**REFUSED**	**DON'T KNOW**
a. First Trimester Nuchal Translucency	○	○	○	○	○	○	○	○	○
b. Chorionic Villus Sampling (CVS)	○	○	○	○	○	○	○	○	○
c. Amniocentesis for genetic testing	○	○	○	○	○	○	○	○	○
d. Screening blood test for Down Syndrome or Spina Bifida	○	○	○	○	○	○	○	○	○
e. Ultrasound	○	○	○	○	○	○	○	○	○
f. Fetal Echocardiogram	○	○	○	○	○	○	○	○	○

	Yes	No	REFUSED	DON'T KNOW	
g. Did the birth mother receive a prenatal diagnosis of the child's heart disease or defect?	○	○	○	○	**-> IF C2 OR C2a IS YES, ASK E1; OTHERWISE END INTERVIEW**

SECTION E: BIOLOGICAL MOTHER'S PREGNANCY HISTORY

The following questions are about the biological mother's pregnancy history.

E1. How many pregnancies, including live births, stillbirths, ectopic pregnancies, induced abortions and miscarriages, has the biological mother had as of today's date, including the child in this study? If she is currently pregnant, please include the current pregnancy in the total number of pregnancies.

E2. How many of the biological mother's pregnancies resulted in live births?

	Yes	No	REFUSED	DON'T KNOW
E3. Were any of the biological mother's pregnancies twins, triplets or other multiple births?	○	○	○	○

a. **IF YES:**How many?

E4. How many living siblings does the child in this study have in total, including full siblings and maternal half-siblings? **-> IF THE NUMBER IN E1=E2 AND E3=NO, END INTERVIEW**

	Yes	No	REFUSED	DON'T KNOW
E5. Has the biological mother had any miscarriages that occurred before 20 weeks of pregnancy?[1]	○	○	○	○

a. **IF YES:**How many?

	Yes	No	REFUSED	DON'T KNOW	
E6. Has the biological mother ended or terminated any pregnancies?[1]	○	○	○	○	**-> IF NO, REFUSED OR DON'T KNOW SKIP TO E7**

a. **IF YES:**How many?

b. FETUS #:

	Yes	No	REFUSED	DON'T KNOW	
i. Was there a cardiac defect?	○	○	○	○	**-> IF NO, REFUSED OR DON'T KNOW SKIP TO E6bii**

a. **IF YES:**Please specify:

b. ENTER CODE FROM TABLE C: View Code List C

	Yes	No	REFUSED	DON'T KNOW	
ii. Was there another abnormality?	○	○	○	○	**-> IF NO, REFUSED OR DON'T KNOW SKIP TO E7**

a. **IF YES:**Please specify:

b. ENTER CODE FROM TABLE A OR TABLE H: View Code List A View Code List H

REMINDER: IF E6a IS MORE THAN ONE, COMPLETE E6b FOR EACH FETUS

	Yes	No	REFUSED	DON'T KNOW	
E7. Did the biological mother ever have a pregnancy longer than 20 weeks in which the fetus died? (LATE MISCARRIAGE)[1]	○	○	○	○	**-> IF NO, REFUSED OR DON'T KNOW END INTERVIEW**

a. **IF YES:**How many?

b. FETUS #:

	Male	Female	REFUSED	DON'T KNOW
i. Was it male or female?	○	○	○	○

	Yes	No	REFUSED	DON'T KNOW	
ii. Was there a cardiac defect?	○	○	○	○	**-> IF NO, REFUSED OR DON'T KNOW SKIP TO E7biii**

a. **IF YES:**Please specify:

b. ENTER CODE FROM TABLE C: View Code List C

	Yes	No	REFUSED	DON'T KNOW	
iii. Was there another abnormality?	○	○	○	○	**-> IF NO, REFUSED OR DON'T KNOW END INTERVIEW**

a. **IF YES:**Please specify:

b. ENTER CODE FROM TABLE A OR TABLE H: View Code List A View Code List H

REMINDER: IF E7a IS MORE THAN ONE, COMPLETE E7b FOR EACH FETUS

[1]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.