Bench to Bassinet
Pediatric Cardiac Genomics Consortium: CHD GENES
Form 109: Medical History and Outcomes Interview, Subject > 1 year
Version: C - 03/09/2011

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. 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. SUBJECT:
- d. LEGAL GUARDIAN:
- e. OTHER:
  - i. IF OTHER, SPECIFY:

SECTION B: PREGNANCY & BIRTH HISTORY

[DIRECT QUESTIONS IN THIS SECTION TO THE MOTHER]
The following questions are about the pregnancy and birth of the subject taking part in this study. Let's begin...

	Yes	No	REFUSED	DON'T KNOW	
B1. Are you the birth mother of the child in this study?					**-> IF YES SKIP TO B2**
a. Do you have any information about the birth mother's pregnancy?					**-> IF YES SKIP TO B2**
b. Was your child adopted?					**-> SKIP TO B7**

B2. What was the method of conception?
- Natural **-> SKIP TO B3**
- Adoption **-> SKIP TO B3**
- Assisted Reproductive Technology **-> SKIP TO B2b**
- Other
- REFUSED **-> SKIP TO B3**
- DON'T KNOW **-> SKIP TO B3**

a. IF OTHER: Please specify: **-> SKIP TO B3**

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?				
v. Donor sperm?				
vi. Donor embryo?				
vii. Surrogate?				
viii. Gestational Carrier?				

B3. How tall are you?

	Feet/inches	Centimeters	REFUSED	DON'T KNOW	
a. Height Unit:	○	○	○	○	**-> IF CENTIMETERS, SKIP TO B3d; -> IF REFUSED OR DON'T KNOW SKIP TO B4**

Feet/inches: b. ____ ft c. ____ in **-> SKIP TO B4**

d. Centimeters: ____ cm

B4. What was your weight before you became pregnant with [SUBJECT'S NAME]?

	Pounds	Kilograms	REFUSED	DON'T KNOW	
a. Weight Unit:	○	○	○	○	**-> IF KILOGRAMS, SKIP TO B4c; -> IF REFUSED OR DON'T KNOW SKIP TO B5**

b. Pounds: ____ lbs **-> SKIP TO B5**

c. Kilograms: ____ kgs

B5. Have you 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 B5b**
IF YES:	**Yes**	**No**	**REFUSED**	**DON'T KNOW**	
i. Did you have this in the 6 months before the pregnancy with [SUBJECT'S NAME]?	○	○	○	○	
ii. Did you 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 B6**
IF YES:	**Yes**	**No**	**REFUSED**	**DON'T KNOW**	
i. Did you have this in the 6 months before the pregnancy with [SUBJECT'S NAME]?	○	○	○	○	
ii. Did you have this during the pregnancy with [SUBJECT'S NAME]?	○	○	○	○	

	Type 1	Type 2	REFUSED	DON'T KNOW
iii. What type of diabetes?	○	○	○	○

	Yes	No	REFUSED	DON'T KNOW	
B6. Did you have gestational diabetes during your pregnancy with [SUBJECT'S NAME]?	○	○	○	○	**-> IF NO, REFUSED, OR DON'T KNOW SKIP TO B7**

IF YES: How was it controlled?

	Yes	No	REFUSED	DON'T KNOW
a. Controlled by diet	○	○	○	○
b. Controlled by medication	○	○	○	○

Now we have a few questions about your child.

B7. How much did your child weigh at birth?

	pounds/ounces	kilograms	REFUSED	DON'T KNOW	
a. Birth Weight Unit:	○	○	○	○	**-> IF KILOGRAMS, SKIP TO B7d; -> IF REFUSED OR DON'T KNOW SKIP TO B8**

Pounds/Ounces: b. ____ lbs c. ____ oz **-> SKIP TO B8**

d. Kilograms: ____ kgs

B8. What was your child's gestational age at birth? **-> IF REFUSED OR DON'T KNOW SKIP TO B9; IF SOURCE PENDING SKIP TO C1**

a. weeks ____

b. days ____

	Yes	No	REFUSED	DON'T KNOW
B9. Was your child born premature?	○	○	○	○

SECTION C: SPECIAL SERVICES

C1. Has your child ever received any of the following services?

	Yes	No	REFUSED	DON'T KNOW	SOURCE PENDING
a. Early Intervention:					
b. Feeding:					
c. Occupational Therapy / Physical Therapy:					
d. Speech:					

C2. Has your child been diagnosed with any of the following disorders?

	Yes	No	REFUSED	DON'T KNOW
a. Behavioral:				

i. **IF YES:** Please specify:

	Yes	No	REFUSED	DON'T KNOW
b. Developmental Delay:				
c. Learning Disability:				
d. Mental Retardation:				
e. Seizure Disorder (not febrile):				
f. Speech Problem:				
g. Attention Deficit Disorder (ADD) / Attention Deficit Hyperactivity Disorder (ADHD):				
h. Anxiety:				
i. Autism Spectrum:				
j. Depression:				
k. Obsessive Compulsive Disorder:				
l. Other Psychological Disorder:				

i. **IF YES:** Please specify:

	Yes	No	REFUSED	DON'T KNOW	SOURCE PENDING
C3. Has your child had an exam by a geneticist (someone who specializes in birth defects)?					
C4. Has your child had genetic testing?					

SECTION D: EDUCATION

COMPLETE SECTION D FOR SUBJECTS OVER 5 YEARS OF AGE

	Yes	No	REFUSED	DON'T KNOW
D1. Is your child currently attending school?				

D2. What is the highest grade of school your child has completed?

- NONE
- PRESCHOOL
- KINDERGARTEN
- 1st GRADE
- 2nd GRADE
- 3rd GRADE
- 4th GRADE
- 5th GRADE
- 6th GRADE
- 7th GRADE
- 8th GRADE
- 9th GRADE
- 10th Grade
- 11th GRADE
- HIGH SCHOOL GRADUATE (PRIVATE PREPARATORY, PAROCHIAL, TRADE OR PUBLIC; GED)
- PARTIAL COLLEGE, 2-YEAR COLLEGE DIPLOMA, OR TRADE SCHOOL
- 3- OR 4-YEAR COLLEGE/UNIVERSITY GRADUATE
- SOME GRADUATE SCHOOL
- POST GRADUATE DEGREE
- EDUCATED IN THE UNITED KINGDOM
- OTHER
- REFUSED
- DON'T KNOW

-> IF D1 IS NO, REFUSED OR DON'T KNOW AND D2 IS NONE, REFUSED OR DON'T KNOW, END INTERVIEW.
-> IF D2 IS EDUCATED IN THE UNITED KINDOM, GO TO D2a
-> IF D2 IS OTHER, GO TO D2b

IF EDUCATED IN THE UK

a. What is the highest grade of school your child has completed?

- NURSERY OR RECEPTION
- YEAR 1
- YEAR 2
- YEAR 3
- YEAR 11, SECONDARY SCHOOL, GCSE LEVEL EDUCATION
- YEAR 12
- YEAR 13, 6th FORM - A LEVELS, BTECs, OCR NATIONALS, OR OTHER VOCATIONAL QUALIFICATIONS

- YEAR 4
- YEAR 5
- YEAR 6, PRIMARY SCHOOL EDUCATION
- YEAR 7
- YEAR 8
- YEAR 9
- YEAR 10
- PARTIAL COLLEGE, 2-YEAR COLLEGE DIPLOMA, OR TRADE SCHOOL
- BACHELOR DEGREE
- SOME GRADUATE SCHOOL
- MASTER DEGREE, DOCTORATE, OR FURTHER DEGREE
- OTHER **> GO TO D2b**
- REFUSED
- DON'T KNOW

b. IF OTHER: Please specify:

	Yes	No	REFUSED	DON'T KNOW	
D3. Did your child repeat any grades?	○	○	○	○	**-> IF YES, GO TO D3a. IF NO, REFUSED OR DON'T KNOW AND ATTENDING SCHOOL, SKIP TO D4; OTHERWISE END INTERVIEW.**

a. **IF YES:** Which grades did your child repeat? **-> IF D1 IS NO, REFUSED OR DON'T KNOW, END INTERVIEW.**

D4. What portion of the day does your child spend in a regular classroom?

- All day
- Most of the day, but not all day (75% to 99%)
- About half of the day (25% to 75%)
- Only a small part of the day (1% to 25%)
- No portion of the day (0%)

	Yes	No	REFUSED	DON'T KNOW	
D5. Does your child currently have an Individualized Education Plan (IEP)?	○	○	○	○	**-> IF NO, REFUSED OR DON'T KNOW, END INTERVIEW.**

IF YES: Which category (or categories) applies to your child?

- a. Hearing impairment ☐
- b. Speech and language impairment ☐
- c. Visual impairment ☐
- d. Orthopedic impairment ☐
- e. Learning disability ☐
- f. Mental retardation ☐
- g. Autism ☐
- h. Emotional disturbance ☐
- i. Psychiatric disability ☐
- j. Multiple disabilities ☐
- k. Traumatic brain injury ☐
- l. Other health impairment ☐