Bench to Bassinet
Pediatric Cardiac Genomics Consortium: CHD GENES
Form 102: Demographics Interview
Version: D - 03/11/2013

SECTION A: ADMINISTRATIVE INFORMATION

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

A1. Study Identification Number: ____

A2. Study Visit: **Proband Subject Baseline Visit**

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

A4. Interview Language:
- ○ ENGLISH
- ○ SPANISH
- ○ OTHER

a. If Other, 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: DEMOGRAPHIC INFORMATION FOR SUBJECT

We will start by asking some questions about your child's background.

B1. What is your child's country of birth? ____ View Country List

	Yes	No	REFUSED	DON'T KNOW
B2. Do you consider your child's ethnicity to be Hispanic or Latino?	○	○	○	○

B3. Do you consider your child to be...
[**INSTRUCTIONS:** READ ALL RACE CHOICES]
- ○ White
- ○ Black or African American
- ○ Asian
- ○ American Indian or Alaskan Native
- ○ Native Hawaiian or other Pacific Islander
- ○ More Than One Race
- ○ Other
- ○ REFUSED
- ○ DON'T KNOW

a. IF MORE THAN ONE RACE: Please say "Yes" to all that apply:
- i. White: ☐
- ii. Black or African American: ☐
- iii. Asian: ☐
- iv. American Indian or Alaskan Native: ☐
- v. Native Hawaiian or other Pacific Islander: ☐
- vi. Other: ☐

b. IF OTHER: Please specify: ____

SECTION C: DEMOGRAPHIC INFORMATION FOR THE SUBJECT'S BIOLOGICAL MOTHER

[DIRECT STATEMENT TO THE MOTHER] Next, we have some questions about your [the subject's biological mother's] background.

C0. BASED ON THE RESPONDENT'S REPLY TO THE STATEMENT ABOVE, CAN YOU COLLECT DEMOGRAPHIC INFORMATION ON THE SUBJECT'S BIOLOGICAL MOTHER?
- ○ YES
- ○ NO

C1. What is your date of birth? _____ *MM/DD/YYYY*

C2. What is your country of birth? _____ View Country List

C3. What is your paternal (biological mother's father) ancestry country of origin? _____ View Country List

C4. What is your maternal (biological mother's mother) ancestry country of origin? _____ View Country List

	Yes	No	REFUSED	DON'T KNOW
C5. Do you consider your ethnicity to be Hispanic or Latino?	○	○	○	○

C6. Do you consider yourself to be...
[**INSTRUCTIONS:** READ ALL RACE CHOICES]

- ○ White
- ○ Black or African American
- ○ Asian
- ○ American Indian or Alaskan Native
- ○ Native Hawaiian or other Pacific Islander
- ○ More Than One Race
- ○ Other
- ○ REFUSED
- ○ DON'T KNOW

a. IF MORE THAN ONE RACE: Please say "Yes" to all that apply:

- i. White: ☐
- ii. Black or African American: ☐
- iii. Asian: ☐
- iv. American Indian or Alaskan Native: ☐
- v. Native Hawaiian or other Pacific Islander: ☐
- vi. Other: ☐

b. IF OTHER: Please specify: _____

C7. What is the highest level of education that you completed?

- ○ KINDERGARTEN-6th GRADE
- ○ 7th-9th GRADE
- ○ 10th OR 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
- ○ POST GRADUATE DEGREE
- ○ EDUCATED IN THE UNITED KINGDOM
- ○ OTHER
- ○ REFUSED
- ○ DON'T KNOW

IF EDUCATED IN THE UK

a. IF EDUCATED IN THE UK: What is the highest level of education that you completed?

- ○ NURSERY - YEAR 7
- ○ YEAR 8 - YEAR 10
- ○ YEAR 11 or YEAR 12, SECONDARY SCHOOL, GCSE LEVEL EDUCATION
- ○ YEAR 13, 6th FORM - A LEVELS, BTECs, OCR NATIONALS, OR OTHER VOCATIONAL QUALIFICATIONS
- ○ PARTIAL COLLEGE, 2-YEAR COLLEGE DIPLOMA, OR TRADE SCHOOL
- ○ BACHELOR DEGREE
- ○ MASTER DEGREE, DOCTORATE, OR FURTHER DEGREE
- ○ OTHER
- ○ REFUSED
- ○ DON'T KNOW

b. IF OTHER: Please specify: _____

SECTION D: DEMOGRAPHIC INFORMATION FOR THE SUBJECT'S BIOLOGICAL FATHER

Next, we have some questions about the father's [the subject's biological father's] background.

D0. BASED ON THE RESPONDENT'S REPLY TO THE STATEMENT ABOVE, CAN YOU COLLECT DEMOGRAPHIC INFORMATION ON THE SUBJECT'S BIOLOGICAL FATHER?

- ○ YES
- ○ NO

D1. What is the father's date of birth? _____ *MM/DD/YYYY*

D2. What is the father's country of birth? _____ View Country List

D3. What is the father's paternal (biological father's father) ancestry country of origin? View Country List

D4. What is the father's maternal (biological father's mother) ancestry country of origin? View Country List

	Yes	No	REFUSED	DON'T KNOW
D5. Do you consider the father's ethnicity to be Hispanic or Latino?	○	○	○	○

D6. Do you consider the father to be...
[**INSTRUCTIONS:** READ ALL RACE CHOICES]

- ○ White
- ○ Black or African American
- ○ Asian
- ○ American Indian or Alaskan Native
- ○ Native Hawaiian or other Pacific Islander
- ○ More Than One Race
- ○ Other
- ○ REFUSED
- ○ DON'T KNOW

a. IF MORE THAN ONE RACE: Please say "Yes" to all that apply:

- i. White: ☐
- ii. Black or African American: ☐
- iii. Asian: ☐
- iv. American Indian or Alaskan Native: ☐
- v. Native Hawaiian or other Pacific Islander: ☐
- vi. Other: ☐

b. IF OTHER: Please specify:

D7. What is the highest level of education that the father completed?

- ○ KINDERGARTEN-6th GRADE
- ○ 7th-9th GRADE
- ○ 10th OR 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
- ○ POST GRADUATE DEGREE
- ○ EDUCATED IN THE UNITED KINGDOM
- ○ OTHER
- ○ REFUSED
- ○ DON'T KNOW

IF EDUCATED IN THE UK

a. IF EDUCATED IN THE UK: What is the highest level of education that the father completed?

- ○ NURSERY - YEAR 7
- ○ YEAR 8 - YEAR 10
- ○ YEAR 11 or YEAR 12, SECONDARY SCHOOL, GCSE LEVEL EDUCATION
- ○ YEAR 13, 6th FORM - A LEVELS, BTECs, OCR NATIONALS, OR OTHER VOCATIONAL QUALIFICATIONS
- ○ PARTIAL COLLEGE, 2-YEAR COLLEGE DIPLOMA, OR TRADE SCHOOL
- ○ BACHELOR DEGREE
- ○ MASTER DEGREE, DOCTORATE, OR FURTHER DEGREE
- ○ OTHER
- ○ REFUSED
- ○ DON'T KNOW

b. IF OTHER: Please specify: