

Medical History

Section A: Cardiac Surgeries

A1. Has the subject had cardiac surgeries? Yes No Unknown

a. If Yes, total number of cardiac surgeries: _____ *(Note: This number should match the number of surgeries recorded below)*

A2. Has the subject had cardiac catheterizations? Yes No Unknown

a. If Yes, total number of cardiac catheterizations: _____

| | | | |
|-----------|--|---|----------------------------------|
| Surgery 1 | A3. Date of Admission for Cardiac Surgery: | _ _ - _ _ - _ _ _ _ _ M M D D Y Y Y Y | <input type="checkbox"/> Unknown |
| | A4. Date of Discharge for Cardiac Surgery: | _ _ - _ _ - _ _ _ _ _ M M D D Y Y Y Y | <input type="checkbox"/> Unknown |
| | A5. Was the surgery open or closed? | <input type="checkbox"/> Open <input type="checkbox"/> Closed | <input type="checkbox"/> Unknown |
| | a. If Open, Date of open surgery: | _ _ - _ _ - _ _ _ _ _ M M D D Y Y Y Y | <input type="checkbox"/> Unknown |
| | A7. Did the subject ever have any surgical complications? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown | |

If Yes, please complete: **Code for Surgical Complication**
(refer to Appendix A: Code for Surgical Complications)

| | | |
|----------------|----------------|----------------|
| M - _ _ _ _ _ | M - _ _ _ _ _ | M - _ _ _ _ _ |
| M - _ _ _ _ _ | M - _ _ _ _ _ | M - _ _ _ _ _ |

| | | | |
|-----------|--|---|----------------------------------|
| Surgery 2 | A3. Date of Admission for Cardiac Surgery: | _ _ - _ _ - _ _ _ _ _ M M D D Y Y Y Y | <input type="checkbox"/> Unknown |
| | A4. Date of Discharge for Cardiac Surgery: | _ _ - _ _ - _ _ _ _ _ M M D D Y Y Y Y | <input type="checkbox"/> Unknown |
| | A5. Was the surgery open or closed? | <input type="checkbox"/> Open <input type="checkbox"/> Closed | <input type="checkbox"/> Unknown |
| | a. If Open, Date of open surgery: | _ _ - _ _ - _ _ _ _ _ M M D D Y Y Y Y | <input type="checkbox"/> Unknown |
| | A7. Did the subject ever have any surgical complications? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown | |

If Yes, please complete: **Code for Surgical Complication**
(refer to Appendix A: Code for Surgical Complications)

| | | |
|----------------|----------------|----------------|
| M - _ _ _ _ _ | M - _ _ _ _ _ | M - _ _ _ _ _ |
| M - _ _ _ _ _ | M - _ _ _ _ _ | M - _ _ _ _ _ |

Surgery 3

A3. Date of Admission for Cardiac Surgery: |_|_| - |_|_| - |_|_|_|_| Unknown
M M D D Y Y Y Y

A4. Date of Discharge for Cardiac Surgery: |_|_| - |_|_| - |_|_|_|_| Unknown
M M D D Y Y Y Y

A5. Was the surgery open or closed? Open Closed Unknown

a. If Open, Date of open surgery: |_|_| - |_|_| - |_|_|_|_| Unknown
M M D D Y Y Y Y

A7. Did the subject ever have any surgical complications? Yes No Unknown

If Yes, please complete: **Code for Surgical Complication**
(refer to Appendix A: Code for Surgical Complications)

M - |_|_|_|_| M - |_|_|_|_| M - |_|_|_|_|

M - |_|_|_|_| M - |_|_|_|_| M - |_|_|_|_|

Surgery 4

A3. Date of Admission for Cardiac Surgery: |_|_| - |_|_| - |_|_|_|_| Unknown
M M D D Y Y Y Y

A4. Date of Discharge for Cardiac Surgery: |_|_| - |_|_| - |_|_|_|_| Unknown
M M D D Y Y Y Y

A5. Was the surgery open or closed? Open Closed Unknown

a. If Open, Date of open surgery: |_|_| - |_|_| - |_|_|_|_| Unknown
M M D D Y Y Y Y

A7. Did the subject ever have any surgical complications? Yes No Unknown

If Yes, please complete: **Code for Surgical Complication**
(refer to Appendix A: Code for Surgical Complications)

M - |_|_|_|_| M - |_|_|_|_| M - |_|_|_|_|

M - |_|_|_|_| M - |_|_|_|_| M - |_|_|_|_|

Surgery 5

A3. Date of Admission for Cardiac Surgery: |__|__| - |__|__| - |__|__|__|__| Unknown
M M D D Y Y Y Y

A4. Date of Discharge for Cardiac Surgery: |__|__| - |__|__| - |__|__|__|__| Unknown
M M D D Y Y Y Y

A5. Was the surgery open or closed? Open Closed Unknown

a. If Open, Date of open surgery: |__|__| - |__|__| - |__|__|__|__| Unknown
M M D D Y Y Y Y

A7. Did the subject ever have any surgical complications? Yes No Unknown

If Yes, please complete: **Code for Surgical Complication**
(refer to Appendix A: Code for Surgical Complications)

M - |__|__|__|__| M - |__|__|__|__| M - |__|__|__|__|

M - |__|__|__|__| M - |__|__|__|__| M - |__|__|__|__|

Surgery 6

A3. Date of Admission for Cardiac Surgery: |__|__| - |__|__| - |__|__|__|__| Unknown
M M D D Y Y Y Y

A4. Date of Discharge for Cardiac Surgery: |__|__| - |__|__| - |__|__|__|__| Unknown
M M D D Y Y Y Y

A5. Was the surgery open or closed? Open Closed Unknown

a. If Open, Date of open surgery: |__|__| - |__|__| - |__|__|__|__| Unknown
M M D D Y Y Y Y

A7. Did the subject ever have any surgical complications? Yes No Unknown

If Yes, please complete: **Code for Surgical Complication**
(refer to Appendix A: Code for Surgical Complications)

M - |__|__|__|__| M - |__|__|__|__| M - |__|__|__|__|

M - |__|__|__|__| M - |__|__|__|__| M - |__|__|__|__|

Section B: Non-Cardiac Surgeries

B1. Did the subject undergo any non-cardiac surgeries? Yes No Unknown

a. If Yes, total number of non-cardiac surgeries: _____

Section C: Events Not Related to Cardiac Surgical Admission

C1. Arrhythmia requiring treatment? Yes No Unknown

a. If Yes, check all that apply:

Cardioversion Pacemaker/defibrillator

Ablation Other, Specify: _____

Medicine

C2. In-hospital Cardiac Arrest? Yes No Unknown

a. If Yes, Date of most recent event: |__|__| - |__|__| - |__|__|__|__|

M M D D Y Y Y Y

C3. Out of hospital Cardiac Arrest? Yes No Unknown

a. If Yes, Date of most recent event: |__|__| - |__|__| - |__|__|__|__|

M M D D Y Y Y Y

C4. Ever on Extracorporeal Membrane Oxygenation (ECMO) in Intensive Care Unit? Yes No Unknown

C5. Ever required Ventricular Assist Device? Yes No Unknown

C6. Current pacemaker? Yes No Unknown

C7. Current defibrillator? Yes No Unknown

Section D: Special Services

D1. Has the subject ever received any of the following services?

a. Early Intervention: Yes Refused

No Don't Know

b. Feeding: Yes Refused

No Don't Know

c. Occupational Therapy / Physical Therapy: Yes Refused

No Don't Know

d. Speech: Yes Refused

No Don't Know

D2. Has the subject been diagnosed with any of the following disorders?

a. Behavioral: Yes Refused
 No Don't Know
 If Yes, Please specify: _____

b. Developmental Delay: Yes Refused
 No Don't Know

c. Learning Disability: Yes Refused
 No Don't Know

d. Intellectual Disability: Yes Refused
 No Don't Know

e. Seizure Disorder (not febrile): Yes Refused
 No Don't Know

f. Speech Problem: Yes Refused
 No Don't Know

g. Attention Deficit Disorder (ADD) / Attention Deficit
 Hyperactivity Disorder (ADHD): Yes Refused
 No Don't Know

h. Anxiety: Yes Refused
 No Don't Know

i. Autism Spectrum: Yes Refused
 No Don't Know

j. Depression: Yes Refused
 No Don't Know

k. Obsessive Compulsive Disorder: Yes Refused
 No Don't Know

l. Other Psychological Disorder: Yes Refused
 No Don't Know
 i. If Yes, Please specify: _____

D3. Did the subject ever take any medications for the treatment of ...

a. Attention / Concentration Yes No
 b. Improve mood Yes No
 c. Anxiety Yes No
 d. Behavior Yes No

D4. Were any neurological abnormalities noted in the medical record? Yes No

If "Yes", check all that apply

a. Absent Corpus Callosum
 b. Chiari Malformation
 c. Dandy-Walker

d. Holoprosencephaly

e. Hydrocephalus

f. Neural Tube Defect

g. Other, specify: _____

D5. Were any genetic syndromes noted in the medical record? Yes No

If "Yes", check all that apply

a. Alagille

b. Cardiofacial Cutaneous

c. Cat Eye

d. CHARGE

e. Cri-du-chat

f. DGS/ VCFS/ CTAF (DGS=DiGeorge Syndrome)

g. Ehlers Danlos

h. Ellis-Van Creveld

i. Goldenhar

j. Holt Oram

k. Jacobsen

l. Kabuki

m. Marfan

n. Microdeletion Syndrome, Specify: _____

o. Microduplication, Specify: _____

p. Noonan

q. Translocation, Specify: _____

r. Trisomy 13

s. Trisomy 18

t. Trisomy 21 (Down)

u. Turner

v. VATER

w. VACTERL

x. Williams

y. Multiple congenital anomalies, NOS

z. Other, specify: _____

D6. Clinical Exam by a geneticist since CHD Genes enrollment? Yes Refused

No Don't Know

D7. Was there a Clinical Genetic test since CHD Genes enrollment? Yes Refused

No Don't Know

APPENDIX A: Code List for Surgical Complications

| CODE | COMPLICATION |
|-------------|--|
| M-0001 | Cardiac arrest |
| M-0002 | Choreoathetosis |
| M-0003 | Coma |
| M-0004 | ECMO |
| M-0005 | Hepatic failure (AST, ALT > 400) |
| M-0006 | Mediastinitis requiring surgery/debridement |
| M-0007 | Unplanned dialysis for renal failure |
| M-0008 | Respiratory arrest |
| M-0009 | Seizures |
| M-0010 | Stroke |
| M-0011 | Unplanned cardiac reoperation without bypass |
| M-0012 | Unplanned cardiac reoperation with bypass |
| M-0013 | Unplanned noncardiac operation |
| M-0014 | Unplanned cardiac catheterization without intervention |
| M-0015 | Unplanned cardiac catheterization with intervention |