Form Approved
OMB Number 0920-XXXX
Exp. Date: XX/XX/20XX

Congenital **H**eart **S**urvey **T**o **R**ecognize **O**utcomes, **N**eeds, and well-bein**G**

[ID STICKER HERE]

BASIC INFORMATION

Any information you give will be confidential. You may skip any questions you do not want to answer.

1. Are you the person to whom the introduction letter was addressed?

- ☐ Yes → ***Go to #4***
- ☐ No

2. What is your relationship to the person to whom the letter was addressed?

- ☐ Partner/Spouse
- ☐ Sibling
- ☐ Parent
- ☐ Other family member
- ☐ Unrelated care giver
- ☐ Other (*please specify*):

3. What is the primary reason that this person cannot complete the questionnaire?

- ☐ Deceased → ***Go to #75 on page 13***
- ☐ Physically unable
- ☐ Mentally unable
- ☐ Unavailable
- ☐ Other (*please specify*):

4. As explained in the letter you received with this survey, we are contacting you about this survey because our records show that you have a congenital heart defect, which is a heart problem you were born with. We would like to ask you some questions about your heart problem.

If you are completing this questionnaire for the addressee (the individual with the heart problem), please answer all questions with information about the addressee only.

What is the name of the heart problem that you were born with? *Mark all that apply.*

- ☐ Aortic valve stenosis
- ☐ Atrial septal defect (ASD)
- ☐ Atrioventricular septal defect (AVSD) or Atrioventricular canal (AV canal)
- ☐ Bicuspid aortic valve
- ☐ Coarctation of aorta
- ☐ Hypoplastic left heart syndrome (HLHS)
- ☐ Patent ductus arteriosus (PDA)
- ☐ Pulmonary atresia
- ☐ Pulmonary valve stenosis
- ☐ Single ventricle (double inlet left ventricle)
- ☐ Tetralogy of Fallot (TOF)
- ☐ Transposition of the great arteries (TGA)
- ☐ Tricuspid atresia
- ☐ Truncus arteriosus
- ☐ Ventricular septal defect (VSD)
- ☐ Other (*please provide name*):
- ☐ Don't know/not sure
- ☐ No heart problem that I know of (*please answer remaining questions to the best of your ability*)

SURGERIES

Next, we will ask you questions about any surgeries you may have had on your heart. Heart surgery will result in scars on the middle of your chest, side, or back. Surgeries that occur after the first surgery may use the same scar or create a new scar.

5. Have you ever had surgery for the heart problem you were born with?

- ☐ Yes
- ☐ No → ***Go to #10***
- ☐ Don't know/not sure → ***Go to #10***

Approximately how many heart surgeries have you had during each of the following age periods? ***Provide number or mark appropriate box.***

	# of Heart Surgeries (enter "0" if no heart surgery)	Had heart surgery but don't know how many	Don't know/ not sure
6. When you were less than 1 year old?		☐	☐
7. When you were 1-5 years old?		☐	☐
8. When you were 6-17 years old?		☐	☐
9. When you were 18 years or older?		☐	☐

HEALTH INSURANCE

The next few questions are about health insurance. When you answer these questions, please think about health insurance obtained through employment or purchased directly, as well as government programs like Medicare and Medicaid that provide medical care or help pay medical bills.

10. Are you covered by health insurance or some other kind of health care plan?

- ☐ Yes
- ☐ No → ***Go to #13 on page 3***
- ☐ Don't know/not sure → ***Go to #13 on page 3***

11. What kind of health insurance or health care coverage do you have? Include those that pay for only one type of service (nursing home care, accidents, or dental care). Exclude private plans that only provide extra cash while hospitalized. *If you have more than one kind of health insurance, mark all that apply.*

- ☐ Private health insurance
- ☐ Medicare
- ☐ Medi-gap
- ☐ Medicaid (state-specific names)
- ☐ SCHIP (CHIP/children's health insurance program)
- ☐ Military health care (Tricare/VA/CHAMP-VA)
- ☐ Indian Health Service
- ☐ State-sponsored health plan
- ☐ Other government program
- ☐ Single service plan (e.g., dental, vision, prescriptions)
- ☐ Other (*please provide name*):

  _____
- ☐ Don't know/not sure

12. In the past 12 months, was there any time when you did not have any health insurance coverage?

- ☐ Yes
- ☐ No
- ☐ Don't know/not sure

13. In regard to your health insurance or health care coverage, how does it compare to a year ago?

- ☐ Better
- ☐ Worse
- ☐ About the same
- ☐ Don't know/not sure

14. Have you ever been denied health insurance?

- ☐ Yes
- ☐ No
- ☐ Don't know/not sure

15. Have you ever <u>received</u> disability benefits (do not include Medicaid)?

- ☐ Yes
- ☐ No
- ☐ Don't know/not sure

16. Have you ever been <u>denied</u> disability benefits (do not include Medicaid)?

- ☐ Yes
- ☐ No
- ☐ Don't know/not sure

17. Have you ever been unable to pay or delayed payment for medical care, including medications, hospital stays, and doctors' visits?

- ☐ Yes
- ☐ No
- ☐ Don't know/not sure

18. Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?

- ☐ Yes
- ☐ No
- ☐ Don't know/not sure

HEALTH CARE

The next set of questions ask about your use of health care.

19. What kind of place do you go most often when you are sick or need advice about your health -- a clinic, doctor's office, emergency room, or some other place? (*Please choose the place you go most often.*)

- ☐ Clinic or health center
- ☐ Doctor's office or HMO
- ☐ Hospital emergency room
- ☐ Hospital outpatient department
- ☐ Some other place
- ☐ Don't go to one place most often → ***Go to #23 on page 5***
- ☐ Don't know/not sure → ***Go to #20***

20. Have you informed the place you go most often when you are sick or need advice about your health that you were born with a heart problem?

- ☐ Yes
- ☐ No

21. At any time in the past 12 months did you <u>change</u> the place where you <u>usually</u> go for health care?

- ☐ Yes
- ☐ No → ***Go to #23 on page 5***
- ☐ Don't know/not sure → ***Go to #23 on page 5***

22. Was this change for a reason related to health insurance?

- ☐ Yes
- ☐ No
- ☐ Don't know/not sure

23. During the past 12 months, how many times have you gone to a hospital emergency room about your own health (this includes emergency room visits that resulted in hospital admission)?

- ☐ None
- ☐ 1
- ☐ 2-3
- ☐ 4-5
- ☐ 6-7
- ☐ 8-9
- ☐ 10-12
- ☐ 13-15
- ☐ 16 or more
- ☐ Don't know/not sure

24. During the past 12 months, how many separate times have you stayed overnight in the hospital for at least one night for any reason? (Only include times when you were admitted to the hospital. Do not include times where you were in the emergency room overnight.)

- ☐ None → ***Go to #26 on page 6***
- ☐ 1
- ☐ 2-3
- ☐ 4-5
- ☐ 6-7
- ☐ 8-9
- ☐ 10-12
- ☐ 13-15
- ☐ 16 or more
- ☐ Don't know/not sure

25. Of these times that you stayed overnight in the hospital for at least one night in the past 12 months, how many were because of your heart problem or complications from your heart problem?

- ☐ None
- ☐ 1
- ☐ 2-3
- ☐ 4-5
- ☐ 6-7
- ☐ 8-9
- ☐ 10-12
- ☐ 13-15
- ☐ 16 or more

26. In the past 12 months, approximately how many times have you visited the office of any health care provider, such as a doctor, nurse, or physician's assistant, for any reason pertaining to your health? Do not include dentists.

- ☐ None → ***Go to #28***
- ☐ 1
- ☐ 2-3
- ☐ 4-5
- ☐ 6-7
- ☐ 8-9
- ☐ 10-12
- ☐ 13-15
- ☐ 16 or more

HEART DOCTORS

The next few questions ask about visits to a heart doctor (cardiologist) or cardiology clinic.

27. How many health care provider visits were with a heart doctor or at a cardiology clinic (clinic that only see patients with heart problems) in the past 12 months?

☐ Please enter a number (enter "0" if none with a heart doctor or at a cardiology clinic)

28. When is the last time you saw a heart doctor?

- ☐ Less than 1 year
- ☐ 1-2 years
- ☐ 3-5 years
- ☐ More than 5 years → ***Go to #30***
- ☐ Never seen one → ***Go to #30***

29. Who are the majority of patients that your primary heart doctor usually sees?

- ☐ Children and adolescents (pediatric cardiologist)
- ☐ Adults who have had their heart problem since birth (adult congenital heart cardiologist)
- ☐ Adults (adult cardiologist)

Go to #31 on page 7

30. If you have <u>not</u> seen a heart doctor in the last 5 years or ever, why? *Mark all that apply.*

- ☐ Felt well
- ☐ Did not think I needed to see a heart doctor
- ☐ Doctor told me I no longer needed to see a heart doctor
- ☐ My parents stopped taking me
- ☐ Changed or lost my insurance
- ☐ Moved to a different city or town
- ☐ Did not like my heart doctor
- ☐ Couldn't find a heart doctor
- ☐ Other

31. When you were a teenager or young adult, did a health care provider ever discuss with you the need to see a heart doctor throughout your life?

- ☐ Yes
- ☐ No

GENERAL HEALTH

The next few questions ask about your physical and mental health and your interactions with others.

32. Have you ever been told by a doctor or other health professional that you had any of the following conditions? (*Mark all that apply*):

- ☐ Diabetes or sugar diabetes
- ☐ Obstructive sleep apnea
- ☐ Cancer or a malignancy of any kind
- ☐ Congestive heart failure
- ☐ Cardiac dysrhythmias or irregular heart beat
- ☐ A mood disorder or depression
- ☐ A heart attack (also called myocardial infarction)
- ☐ A stroke
- ☐ Asthma
- ☐ An ulcer (stomach, duodenal or peptic ulcer)
- ☐ Arthritis, gout, lupus, or fibromyalgia
- ☐ Hypertension, also called high blood pressure
- ☐ Other (*please specify*):
- ☐ None of the above

Mark the box that corresponds to your answer for questions 33 – 38.

	Excellent	Very Good	Good	Fair	Poor
33. In general, would you say your health is:	☐	☐	☐	☐	☐
34. In general, would you say your quality of life is:	☐	☐	☐	☐	☐
35. In general, how would you rate your physical health?	☐	☐	☐	☐	☐
36. In general, how would you rate your mental health, including your mood and your ability to think?	☐	☐	☐	☐	☐
37. In general, how would you rate your satisfaction with your social activities and relationships?	☐	☐	☐	☐	☐
38. In general, please rate how well you carry out your usual social activities and roles (this includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)?	☐	☐	☐	☐	☐

39. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

- ☐ Completely
- ☐ Mostly
- ☐ Moderately
- ☐ A little
- ☐ Not at all

40. <u>In the past 7 days</u>, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

41. <u>In the past 7 days</u>, how would you rate your fatigue on average?

- ☐ None
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Very severe

42. <u>In the past 7 days</u>, how would you rate your pain on average? *Mark the box that corresponds to your answer.*

No pain ← → Worst pain imaginable

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

<u>Over the last 2 weeks</u>, how often have you been bothered by any of the following problems? *Mark the box that corresponds to your answer.*

	Not at all	Several days	More than half the days	Nearly every day
43. Little interest or pleasure in doing things	☐	☐	☐	☐
44. Feeling down, depressed, or hopeless	☐	☐	☐	☐

With the next set of questions, we want to learn whether you have physical, mental, or emotional conditions that cause serious difficulties with your daily activities.

45. Are you deaf or do you have serious difficulty hearing?

- ☐ Yes
- ☐ No

46. Are you blind or do you have serious difficulty seeing, even when wearing glasses?

- ☐ Yes
- ☐ No

47. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

- ☐ Yes
- ☐ No

48. Do you have serious difficulty walking or climbing stairs?

- ☐ Yes
- ☐ No

49. Do you have difficulty dressing or bathing?

- ☐ Yes
- ☐ No

50. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

- ☐ Yes
- ☐ No

Please rate how concerned you are about the following.

	Not at all concerned	Not very concerned	Somewhat concerned	Very concerned
51. Your future health	☐	☐	☐	☐
52. Your ability to have children	☐	☐	☐	☐
53. Your overall heart health	☐	☐	☐	☐

54. Have you completed an advance health care directive, living will, or heath care power of attorney?

- ☐ Yes
- ☐ No
- ☐ Don't know/not sure

HEIGHT AND WEIGHT

Questions 55 – 57 ask about your height and weight.

55. How tall are you without shoes?

Height in feet and inches (*please give number*) _____ **ft.** _____ **in.**

56. How much do you weigh without clothes or shoes? If you are currently pregnant, how much did you weigh before your pregnancy?

Weight in pounds (*please give number*) _____ **pounds**

57. What is the most you have ever weighed in your life? (*Do not include any times when you were pregnant.*)

Weight in pounds (*please give number*) ☐ **pounds**

REPRODUCTIVE HEALTH

This section is for women only. If you are a man, go to #65 on page 11.

Now we will ask you questions about your reproductive health in relation to your heart problem and any pregnancies you have had or are planning.

58. Has a doctor, nurse, or other health care worker ever talked with you about special concerns about becoming pregnant because of your heart problem?

- ☐ Yes
- ☐ No

59. Has a doctor, nurse, or other health care worker ever advised you to avoid pregnancy because of your heart problem?

- ☐ Yes
- ☐ No

60. Has a doctor, nurse or other health professional ever talked with you about the safest type of birth control or contraception to use because of your heart problem?

- ☐ Yes
- ☐ No

61. Have you ever delayed or avoided getting pregnant because of concerns about your health in relation to your heart problem?

- ☐ Yes
- ☐ No

62. Have you ever been pregnant?

- ☐ Yes
- ☐ No → ***Go to #65 on page 11***
- ☐ Don't know/not sure → ***Go to #65 on page 11***

63. How many times have you been pregnant?

☐ Please enter a number

64. How many times have you given birth?

☐ Please enter a number (*enter "0" if never given birth*)

RECORD CONFIRMATION

Now we would like to confirm the information we have in our records and understand how people who completed the survey differ from other people born with a heart problem. Similar to all questions in this survey, any information you give will be confidential. You may skip any questions you do not want to answer. If you are not the person to whom the letter was addressed, please answer with information about the addressee only (that is, the person to whom the introduction letter was addressed).

65. Do you consider yourself to be Hispanic or Latino?

- ☐ Yes
- ☐ No

66. What race or races do you consider yourself to be? *One or more categories may be selected.*

- ☐ American Indian or Alaskan Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or Pacific Islander
- ☐ White

67. How many times have you been married (or lived as married)?

☐ Please enter a number (*enter "0" if never been married or lived as married*)

EDUCATION AND WORK HISTORY

Questions 68 – 73 ask about your education and work history.

68. What is the highest degree or grade you have completed?

- ☐ Never attended school or only attended kindergarten
- ☐ Less than 9th grade
- ☐ 9th to 12th grade, no diploma
- ☐ High school graduate, GED, or alternative
- ☐ Some college, no degree
- ☐ Associate degree
- ☐ Bachelor's degree
- ☐ Graduate or professional degree
- ☐ Don't know/not sure

69. In elementary, junior, or high school were you ever in a special education program? *Mark all that apply.*

- ☐ Special education
- ☐ Advanced placement
- ☐ Homebound education
- ☐ Not in any of these programs → ***Go to #71***
- ☐ Don't know/not sure → ***Go to #71***

70. If you were in a special education program, what grades were you in at the time? *Mark all that apply.*

- ☐ Kindergarten-3rd grade
- ☐ 4th-6th grade
- ☐ 7th-12th grade
- ☐ Don't know/not sure

71. During the last 12 months, did you work for pay at any time at a job or business? *Mark all that apply.*

- ☐ Yes – Full time
- ☐ Yes – Part time
- ☐ No

72. Has your health kept you from serving in military service or from doing the type of work that you want?

- ☐ Yes
- ☐ No
- ☐ Still in school

73. During the last 12 months, approximately how many days of school or work did you miss because of illness?

☐ Please enter a number
(*enter "0" if did not miss school or work because of illness in last 12 months*)

☐ I do not attend school nor do I work for pay.

74. For future planning, what type of information or help do you think should be available to people born with heart problems?

Please continue to the next page.

CONTACT INFORMATION

Finally, we would like some information from you to confirm our records. If you are not the person to whom the letter was addressed, please answer with information about the addressee only (that is, the person to whom the introduction letter was addressed).

75. What name were you given at birth? Please enter both first and last name.

(*Please print*)

76. If your name has changed since birth, what is your current name? Please enter both first and last name.

(*Please print*)

77. What is your date of birth?

mm *dd* *yyyy*

We want to thank you again for participating in this survey. As the survey progresses, we would like to provide you updates about what we learn. Also, the CDC may conduct similar surveys in the future, and would like to offer you an opportunity to participate. Please remember that, if you provide your contact information now, you may change your mind and decline participation in the future.

78. If you would like to receive periodic updates on the progress and results of this survey, please provide your email address.

Email address
(*please print*)

79. May we contact you in the future to participate in similar surveys?

- ☐ Yes
- ☐ No → ***Go to the end***

80. Please provide your current mailing address and/or email address, depending on how you would like to be contacted. (*please print*)

Street address

City State Zip

Email address

81. It would be helpful if you could provide us with the name and address of someone who could give us your new address in case you decide to move in the future. We would contact this person for your new address only if we are unable to reach you at your home address and/or email address. (*please print*)

Street address

City State Zip

Email address

Thank you for your time. It is truly appreciated.

[ID STICKER HERE]

Please return this questionnaire in the provided postage-paid envelope.
If you have lost your envelope, please return to:
Centers for Disease Control and Prevention
4770 Buford Hwy
Mailstop E-86 (Attn: Sherry Farr)
Atlanta, GA 30341

If you have any questions or comments, please visit our website:
www.chstrong.org

or contact:
The CH STRONG Project Manager at
info@chstrong.org or (800) 586-5505