Form Approved OMB No. 0920-XXXXX Exp.: XX/XX/20XX

Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG (CH STRONG)

Questions 1-3 ask basic information about you to make sure we have the right person.

- 1. Are you the person to whom the introduction letter was addressed?
 - a. Yes (Skip to Question 4)
 - b. No
- 2. If no, what is your relationship to the person to whom the letter was addressed?
 - a. Partner/Spouse
 - b. Sibling
 - c. Parent
 - d. Other family member
 - e. Unrelated care giver
 - f. Other, please specify:

(please print)

- 3. What is the primary reason that this person cannot complete the questionnaire?
 - a. Physically unable
 - b. Mentally unable
 - c. Deceased (Skip to Q 70)
 - d. Unavailable
 - e. Other, please specify:______

(please print)

As explained in the letter you received, 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, please answer all questions with information about the addressee only.

- 4. What is the name of the heart problem that you were born with? (Check all that apply.)
 - a. Aortic valve stenosis
 - b. Atrial septal defect (ASD)
 - c. Atrioventricular septal defect (AVSD) or Atrioventricular canal (AV canal)
 - d. Bicuspid aortic valve
 - e. Coarctation of aorta

Public reporting burden of this collection information is estimated to average 20 minutes, including completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ ATSDR Reports Clearance Officer, 1600 Clifton Road NE, MS D-74, Atlanta, GA 30333: ATTN: PRA (0920-XXXX).

- f. Hypoplastic left heart syndrome (HLHS)
- g. Pulmonary atresia
- h. Pulmonary valve stenosis
- i. Tetralogy of Fallot (TOF)
- j. Transposition of the great arteries (TGA)
- k. Tricuspid atresia
- I. Ventricular septal defect (VSD)
- m. Truncus arteriosus
- n. Single ventricle (double inlet left ventricle)
- o. Patent ductus arteriosus (PDA)
- p. Other please provide name (please print)

- q. Don't know/not sure
- r. No heart problem that I know of (Please answer remaining questions to the best of your ability.)

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?
 - a. Yes
 - b. No (Skip to Question 7)
 - c. Not sure (Skip to Question 7)
- 6. Approximately how many heart surgeries have you had during each of the following age periods? (Provide number or check appropriate box.)

	Number of Surgeries (0 if no surgery)	Had surgery but don't know how many	Don't know/not sure
When you were less than 1 year old?			
When you were 1-5 years old?			
When you were 6-17 years old?			
When you were 18 years or older?			

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.

- 7. Are you covered by health insurance or some other kind of health care plan?
 - a. Yes
 - b. No (Skip to Question 10)

- c. Don't know/not sure (Skip to Question 10) 8. 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, please select all that apply. a. Private health insurance b. Medicare c. Medi-gap d. Medicaid (state-specific names) e. SCHIP (CHIP/children's health insurance program) f. Military health care (Tricare/VA/CHAMP-VA) g. Indian Health Service h. State-sponsored health plan i. Other government program j. Single service plan (e.g., dental, vision, prescriptions) k. No coverage of any type I. Other, please specify ____ (please print) m. Don't know/not sure 9. In the past 12 months, was there any time when you did not have any health insurance coverage? a. Yes b. No c. Don't know/not sure 10. In regard to your health insurance or health care coverage, how does it compare to a year ago? a. Better b. Worse c. About the same d. Don't know/not sure 11. Have you ever been denied health insurance? a. Yes b. No c. Don't know/not sure 12. Have you ever received disability benefits (do not include Medicaid)? a. Yes b. No c. Don't know/not sure
- 13. Have you ever been $\underline{\text{denied}}$ disability benefits (do not include Medicaid)?
 - a. Yes

- b. No
- c. Don't know/not sure
- 14. Have you ever been unable to pay or delayed payment for medical care, including medications, hospital stays, and doctors' visits?
 - a. Yes
 - b. No
 - c. Don't know/not sure
- 15. Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?
 - a. Yes
 - b. No
 - c. Don't know/not sure

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

- 16. 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.)
 - a. Clinic or health center
 - b. Doctor's office or HMO
 - c. Hospital emergency room
 - d. Hospital outpatient department
 - e. Some other place
 - f. Don't go to one place most often (Skip to Question 20)
 - g. Don't know/not sure
- 17. 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?
 - a. Yes
 - b. No
 - c. Don't know/not sure
- 18. At any time in the past 12 months did you CHANGE the place where you USUALLY go for health care?
 - a. Yes
 - b. No (Skip to Question 20)
 - c. Don't know/not sure (Skip to Question 20)
- 19. Was this change for a reason related to health insurance?
 - a. Yes
 - b. No
 - c. Don't know/not sure
- 20. 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)?

i.	16 or more
j.	Don't know/not sure
21. During	the past 12 months, how many separate times have you stayed overnight in the hospital for at
least o	ne night for any reason? (Only include times when you were admitted to the hospital. Do not
include	e times where you were in the emergency room overnight.)
a.	None (Skip to Question 23)
b.	1
c.	2-3
d.	4-5
e.	6-7
f.	8-9
g.	10-12
h.	13-15
i.	16 or more
_	Don't know/not sure
how m	se times that you stayed overnight in the hospital for at least one night in the past 12 months, any were because of your heart problem or complications from your heart problem?
22. Of the	se times that you stayed overnight in the hospital for at least one night in the past 12 months,
22. Of the	se times that you stayed overnight in the hospital for at least one night in the past 12 months,
22. Of the how m	se times that you stayed overnight in the hospital for at least one night in the past 12 months, any were because of your heart problem or complications from your heart problem?
22. Of the how m a. b. c.	se times that you stayed overnight in the hospital for at least one night in the past 12 months, any were because of your heart problem or complications from your heart problem? None 1 2-3
22. Of the how m a. b. c. d.	se times that you stayed overnight in the hospital for at least one night in the past 12 months, rany were because of your heart problem or complications from your heart problem? None 1 2-3 4-5
22. Of the how m a. b. c. d. e.	se times that you stayed overnight in the hospital for at least one night in the past 12 months, nany were because of your heart problem or complications from your heart problem? None 1 2-3 4-5 6-7
22. Of the how m a. b. c. d.	se times that you stayed overnight in the hospital for at least one night in the past 12 months, rany were because of your heart problem or complications from your heart problem? None 1 2-3 4-5
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22. Of the how m a. b. c. d. e. f. g. h. i. j.	se times that you stayed overnight in the hospital for at least one night in the past 12 months, rany 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 Don't know/not sure past 12 months, approximately how many times have you visited the office of any health care
22. Of the how m a. b. c. d. e. f. g. h. i. j. 23. In the provid not income	se times that you stayed overnight in the hospital for at least one night in the past 12 months, nany 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 Don't know/not sure past 12 months, approximately how many times have you visited the office of any health care er, such as a doctor, nurse, or physician's assistant, for any reason pertaining to your health? I
22. Of the how m a. b. c. d. e. f. g. h. i. j. 23. In the provid not inc. a.	se times that you stayed overnight in the hospital for at least one night in the past 12 months, nany 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 Don't know/not sure past 12 months, approximately how many times have you visited the office of any health care er, such as a doctor, nurse, or physician's assistant, for any reason pertaining to your health? Edude dentists.

a. None
b. 1
c. 2-3
d. 4-5
e. 6-7
f. 8-9
g. 10-12
h. 13-15

- d. 4-5
- e. 6-7
- f. 8-9
- g. 10-12
- h. 13-15
- i. 16 or more
- j. Don't know/not sure

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

- 24. How many of these visits were with a heart doctor or at a cardiology clinic (clinic that only sees patients with heart problems) in the past 12 months?
 - a. Please enter a number (enter "0" if none with a heart doctor or at a cardiology clinic):
 - b. Don't know/not sure
- 25. When is the last time you saw a heart doctor?
 - a. Less than 1 year
 - b. 1-2 years
 - c. 3-5 years
 - d. More than 5 years (Skip to Question 27)
 - e. Never seen one (Skip to Question 27)
 - f. Don't know/not sure
- 26. Who are the majority of patients that your primary heart doctor usually sees?
 - a. Children and adolescents (pediatric cardiologist) (Skip to Question 28)
 - b. Adults who have had their heart problem since birth (adult congenital heart cardiologist) (Skip to Question 28)
 - c. Adults (adult cardiologist) (Skip to Question 28)
 - d. Don't know/not sure (Skip to Question 28)
- 27. If you have <u>not</u> seen a heart doctor in the last 5 years or ever, why? Please check all that apply.
 - a. Felt well
 - b. Did not think I needed to see a heart doctor
 - c. Doctor told me I no longer needed to see a heart doctor
 - d. My parents stopped taking me
 - e. Changed or lost my insurance
 - f. Moved to a different city or town
 - g. Did not like my heart doctor
 - h. Couldn't find a heart doctor
 - i. Other
 - j. Don't know/not sure
- 28. 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?

- a. Yes
- b. No
- c. Don't know/not sure

The next few questions ask about your physical and mental health and your interactions with others. Please place an X in the box that corresponds to your answer.

		Excellent	Very Good	Good	Fair	Poor
29.	In general, would you say your health is:					
30.	In general, would you say your quality of life is:					
31.	In general, how would you rate your physical health?					
32.	In general, how would you rate your mental health, including your mood and your ability to think?					
33.	In general, how would you rate your satisfaction with your social activities and relationships?					
34.	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)?					

- 35. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?
- a. Completely
- b. Mostly
- c. Moderately
- d. A little
- e. Not at all
- 36. <u>In the past 7 days</u>, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?
- a. Never
- b. Rarely
- c. Sometimes
- d. Often
- e. Always

that corresp		days, how s to your		•	your pain	i on averag	ge? Please p	nace a cne		iii tiic box
No pain	←								-	Worst pain imaginable
0 1	1	2	3	4	5	6	7			- 0
								ne followin	g proble	ms? Please
39. <u>Over th</u> place a che								ne followin	g proble	ms? Please
	ck ma		box tha		onds to yo	our answei	choice.	ne followin		
place a che	ck ma	ark in the	box tha	t correspo	onds to yo	More t	choice.			
place a che Little intere or pleasure	ck ma	ark in the	box tha	t correspo	onds to yo	More t	choice.			
place a che Little intere or pleasure in doing	ck ma	ark in the	box tha	t correspo	onds to yo	More t	choice.			
Little intere or pleasure in doing things	ck ma	ark in the	box tha	t correspo	onds to yo	More t	choice.			
place a che Little intere or pleasure in doing	ck ma	ark in the	box tha	t correspo	onds to yo	More t	choice.			
Little intere or pleasure in doing things Feeling	est	ark in the	box tha	t correspo	onds to yo	More t	choice.			

37. In the past 7 days, how would you rate your fatigue on average?

a. Noneb. Mildc. Moderate

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

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

a. Yes

a. Yesb. No

a. Yesb. No

that cause serious difficulties with your daily activities.

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

b. No

	b. No				
44.	Do you have difficulty dres a. Yes b. No	sing or bathing?			
Please	Because of a physical, men visiting a doctor's office or a. Yes b. No	shopping?			
to your	answer choice.):			<u> </u>	
		Not at all concerned	Not very concerned	Somewhat concerned	Very concerned
46.	Your future health				
47.	Your ability to have children				
48.	Your overall heart health				
49.	Have you completed an ad a. Yes b. No c. Don't know/not su		directive, living will,	or heath care powe	r of attorney?
Questic	ons 50-52 ask about your he	ight and weight.			
50.	How tall are you without s a. Height in feet and b. Height in meters o c. Don't know/not su	inches (please give r centimeters (plea	number)ft	in.	
51.	How much do you weigh w weigh before your pregnar a. Weight in pounds	ncy? Please answe	r in either pounds o	r kilograms, not bot	•

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

a. Yes

		Weight in kilograms (please give number)kilograms Don't know/not sure
52.	pregna a. b.	the most you have ever weighed in your life? [Do not include any times when you were nt.] Please answer in either pounds or kilograms, not both. Weight in pounds (please give number)pounds Weight in kilograms (please give number)kilograms Don't know/not sure
Men-Sk	kip to qu	estion 60
	-	Now we will ask you questions about your reproductive health in relation to your heart problem incies you have had or are planning.
53.	becom a. b.	loctor, nurse, or other health care worker ever talked with you about special concerns about ing pregnant because of your heart problem? Yes No Don't know/not sure
54.	heart p a. b.	loctor, nurse, or other health care worker ever advised you to avoid pregnancy because of your problem? Yes No Don't know/not sure
55.	control a. b.	loctor, nurse or other health professional ever talked with you about the safest type of birth or contraception to use because of your heart problem? Yes No Don't know/not sure
	your he a. b. c.	ou ever delayed or avoided getting pregnant because of concerns about your health in relation to eart problem? Yes No Don't know/not sure ou ever been pregnant?
	a.	Yes No (Skip to Question 60) Don't know/not sure (Skip to Question 60)
58.	How m	any times have you been pregnant? Please enter a number:

	ny times have you given birth? Please enter a number (enter "0" if never given birth):
completed the sany information not the person to	ike to confirm the information we have in our records and understand how people who urvey differ from other people born with a heart problem. Similar to all questions in this survey, you give will be confidential. You may skip any questions you do not want to answer. If you are o whom the letter was addressed, please answer with information about the addressee only on to whom the introduction letter was addressed).
60. Do you a.	consider yourself to be Hispanic or Latino? Yes

- 61. What race or races do you consider yourself to be? Please select one or more.
 - a. American Indian or Alaska Native
 - b. Asian

b. No

c. Black or African American

c. Don't know/not sure

- d. Native Hawaiian or Pacific Islander
- e. White
- f. Don't know/not sure
- 62. How many times have you been married (or lived as married)?
 - a. Please enter a number (enter "0" if never been married or lived as married):

Questions 63 through 68 ask about your education and work history.

- 63. What is the highest degree or grade you have completed?
 - a. Never attended school or only attended kindergarten
 - b. Less than 9th grade
 - c. 9th to 12th grade, no diploma
 - d. High school graduate, GED, or alternative
 - e. Some college, no degree
 - f. Associate degree
 - g. Bachelor's degree
 - h. Graduate or professional degree
 - i. Don't know/not sure
- 64. In elementary, junior, or high school were you ever in a special education program? Please select all that apply.
 - a. Special education

C.	Advanced placement
	Homebound education
d.	Not in any of these programs (Skip to Question 66)
	Don't know/not sure (Skip to Question 66)
65. If you w	vere in a special education program, what grades were you in at the time? Please select all th
apply.	
a.	Kindergarten-3rd grade
b.	4th-6th grade
c.	7th-12th grade
d.	Don't know/not sure
66. During	the last 12 months, did you work for pay at any time at a job or business? Please select all the
apply.	
a.	Yes- Full time
b.	Yes – Part time
c.	No
d.	Don't know/not sure
67. Has you	ır health kept you from serving in military service or from doing the type of work that you wa
a.	Yes
b.	No
c.	Still in school
d.	Don't know/not sure
68. During illness?	the last 12 months, approximately how many days of school or work did you miss because of
a.	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.

Finally,	we would like some	information from	om you to co	onfirm our re	cords. If you are not the person t	o whom the
letter w	as addressed, please	e answer with i	nformation a	about the add	dressee only (that is, the person t	o whom the
introdu	ction letter was addr	essed).				
70.	What name were yo	ou given at birtl	h?			
					(please print)	
71	If your name has ab	angad sinca hir	th what is w	our current n	ama?	
/1.	If your name has ch	angeu since bii	tii, Wiiat is y	our current ii	(please print)	
					(piease print)	
72.	What is your date o	f birth?				
	Month	Day	Year			
	Worth	Day	icai			
-	y change your mind a If you would like to your email address.				s and results of this survey, please	provide
Γm	ail addrass (plaasa p	rin+\.				
EM	ali address (piease pi	rint):				
74.	May we contact you Yes No	ı in the future t	o participate	in similar su	rveys?	
75.	If yes, please provid like to be contacted	-	mailing addr	ess and/or er	nail address, depending on how y	ou would
	(street address)	(c i	ity)	(state)	(zip code)	

Email address (please print):

•	w address in case you de o reach you at your hom			•	on only if we are
		(N	ame)		
((street address)	(city)	(state)	(zip code)	_

76. It would be helpful if you could provide us with the name and address of someone who could give us

Thank you for your time. It is truly appreciated.