

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

Form Approved
OMB No. : 0920-XXXX

Exp.: XX/XX/20XX

Thank you for taking part in CHSTRONG, a survey to examine the healthcare needs of people born with heart conditions. This project is being conducted by the <<sites>>, the March of Dimes, and the Centers for Disease Control and Prevention (CDC)

Across the country, hundreds of people born with a heart condition are taking part in this survey. Everyone's answers are important to us and will add to our understanding of how heart conditions affect adults. The findings from the survey will help identify unmet needs of adults who were born with heart conditions. Additionally, this information may help families of children born with heart conditions plan for the future. To learn more about this project, you can visit <<Website address>>.

The survey will take about 20 minutes. Your participation in this the survey is up to you. If you choose to participate, it would be helpful if you completed all of the questions. However, you can decide not to answer any question and you can stop at any time. Nothing will happen if you decide not to complete the survey. Your answers are confidential and your name will never be released.

If you have any questions, please contact
Dr. Sherry Farr
National Center on Birth Defects and Developmental Disabilities, CDC
<<800.xxx.xxxx>>

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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).



Basic Information

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?

- Yes)
- No

Clear radio button

|

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Basic Information

2. If no, what is your relationship to the person to whom the letter was addressed?

- P. ct: n\$.P.9. :i
- Sibling
- Parent
- Other family member
- Unrelated care giver _____
- Other, please specify _____

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

- Physically unable
- Mentally unable
- Deceased
- Unavailable _____
- Other, please specify _____

Clear radio button

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Basic Information

As explained in the letter you received, we are contacting you about this survey because our records show that you have a congenital heart problem, 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)

Aortic j 9 11

Atrial septal defect (ASD)

Atrioventricular septal defect (AVSD) or Atrioventricular canal (AV canal)

Bicuspid aortic valve

Coarctation of aorta

Hypoplastic left heart syndrome (HLHS)

Pulmonary atresia

Pulmonary valve stenosis

Tetralogy of Fallot (TOF)

Transposition of the great arteries (TGA)

Tricuspid atresia

Ventricular septal defect (VSD)

Truncus arteriosus

Single ventricle (double inlet left ventricle)

Patent ductus arteriosus (PDA)

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
- Not sure

Clear radio button

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Surgeries

6. Approximately how many heart surgeries have you had during each of the following age periods? (Provide number or check box for "Don't know")

	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?	<input type="checkbox"/>	<input type="checkbox"/> D	<input type="checkbox"/> D
When you were 1-5 years old?	<input type="checkbox"/>	<input type="checkbox"/> D	<input type="checkbox"/> D
When you were 6-17 years old?	<input type="checkbox"/>	<input type="checkbox"/> D	<input type="checkbox"/> D
When you were 18 years or older?	<input type="checkbox"/>	<input type="checkbox"/> D	<input type="checkbox"/> D

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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.

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

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

Clear radio button

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Health Insurance

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.

Private ()

Medicare

Medi-gap

Medicaid (state-specific names)

SCHIP (CHIP/children's health insurance program)

Military health care (Tricare/NCHAMP-VA)

Indian Health Service

State-sponsored health plan

Other government program

Single service plan (e.g., dental, vision, prescriptions)

No coverage of any type _____

Other - please provide name _____

Don't know/ not sure

9. 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

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Health Insurance

10. 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

11. Have you ever been denied health insurance?

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

12. Have you ever received disability benefits (do not include Medicaid)?

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

13. Have you ever been denied disability benefits (do not include Medicaid)?

- Yes
- No
- 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?

- Yes
- No
- 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?

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

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Health Care

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)

- Doctor's office or HMO
- Hospital emergency room
- Hospital outpatient department
- Some other place
- Don't go to one place most often
- Don't know/ not sure

Clear radio button

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HealthCare

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

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

18. At any time in the past 12 months did you CHANGE the place(s) to which you USUALLY go for health care?

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

Clear radio button

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Health Care

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

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

Clear radio button

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Health Care

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)?

0 f.iqtj:

- 1
- 2-3
- 4-5
- 6-7
- 8-9
- 10-12
- 13-15
- 16 or more
- 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 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
- 1
- 2-3
- 4-5
- 6-7
- 8-9
- 10-12
- 13-15
- 16 or more
- Don't know/ not sure

Clear radio button

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Health Care

22. 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?

of.iqtj:

- 1
- 2-3
- 4-5
- 6-7
- 8-9
- 10-12
- 13-15
- 16 or more
- Don't know/ not sure

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Health Care

23. 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.

of.iqtj :

- 1
- 2-3
- 4-5
- 6-7
- 8-9
- 10-12
- 13-15
- 16 or more
- Don't know/ not sure

Clear radio button

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Heart Doctors

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?

Please enter a number (enter "0" if none with a heart doctor or at a cardiology clinic in the last 12 months)

Don't know/not sure

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Heart Doctors

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

1-2 years

3-5 years

More than 5 years

Never seen one

Don't know/not sure

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Heart Doctors

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

- Children (under 18 years old)
- Adults who have had their heart problem since birth (adult congenital heart cardiologist)
- Adults (adult cardiologist)
- Don't know/ not sure

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Heart Doctors

27. If you have not seen a heart doctor in the last 5 years or ever, why? Please check all that apply.

- f. .WII
- 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
- Don't know/ not sure

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Heart Doctors

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?

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

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General Health

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

Please mark the box that corresponds to your answer.

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

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General Health

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?

0. ifn PitY.:

- Mostly
- Moderately
- A little
- Not at all

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

- Never
- Rarely
- Sometimes
- Often
- Always

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

- None
- Mild
- Moderate
- Severe
- Very severe

Clear radio button

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General Health

38. In the past 7 days, how would you rate your pain on average?

No pain 0	1	2	3	4	5	6	7	8	9	Worst pain imaginable 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

39. Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling down, depressed, or hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Clear radio button

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General Health

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.

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

- Yes
- No

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

- Yes
- No

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

- Yes
- No

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

- Yes
- No

44. Do you have difficulty dressing or bathing?

- Yes
- No

45. 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

Clear radio button

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General Health

Please rate how concerned you are about the following

	Not at all concerned	Not very concerned	Somewhat concerned	Very concerned
46. Your future health	<input type="radio"/> ; <input type="radio"/> ;	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. Your ability to have children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48. Your overall heart health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

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

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Height And Weight

Questions 50-52 ask about your height and weight

50. How tall are you without shoes? Please answer in either feet or meters, not both.

Height in feet and inches (please give number)jft in

Height in meters or centimeters (please give number)jm cm.

Don't know/not sure

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Height And Weight

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

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Height And Weight

52. What is the most you have ever weighed in your life? (Do not include any times when you were pregnant) Please answer in either pounds or kilograms, not both.

Weight in pounds (please give number)

Weight in kilograms (please give number)

Don't know/ not sure

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Reproductive Health

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

53. 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
- Don't know/ not sure

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

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

55. 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
- Don't know/ not sure

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

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

57. Have you ever been pregnant?

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

Clear radio button

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Reproductive Health

58. How many times have you been pregnant?

Please enter a number (enter "0" if never pregnant)

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Reproductive Health

59. How many times have you given **birth**?

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

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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 wish 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)

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

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

61. What race or races do you consider yourself to be? Please select one or more.

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Pacific Islander
- White
- Don't know/ not sure

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

(enter "0" if never been married or lived as married)

Clear radio button

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Education And Work History

Questions 63 through 68 ask about your education and work history

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

- 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

64. In elementary, junior, or high school were you ever in a special education program? Please select all that apply.

- Special education
- Advanced placement
- Homebound education
- Not in any of these programs
- Don't know/ not sure

Clear radio button

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Education And Work History

65. If you were in a special education program, what grades were you in at the time? Please select all that apply.

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

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Education And Work History

66. During the last 12 months, did you work for pay at any time at a job or business? Please select all that apply.

- Yes - Full time
- Yes - Part time
- No
- Don't know/ not sure

67. 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
- Don't know/not sure

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

(enter "0" if did not miss school or work because of illness in the last 12 months)

I do not attend school nor do I work for pay

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

Clear radio button

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Contact Information

Finally, we would like your contact information 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)

70. What name were you given at birth?

^
T

71. If your name has changed since birth, what is your current name?

^
T

72. 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.

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

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

Contact Information

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

- Yes
- No

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Contact Information

75. Please provide your current mailing address and/or email address, depending on how you would like to be contacted.

Street Address	<input type="text"/>	^ T
City	<input type="text"/>	^ T
State	<input type="text"/>	^ T
Zip	<input type="text"/>	^ T
E-Mail Address	<input type="text"/>	^ T

76. 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 only if we are unable to reach you at your home address and/or email address.

Name	<input type="text"/>	^ T
Street Address	<input type="text"/>	^ T
City	<input type="text"/>	^ T
State	<input type="text"/>	^ T
Zip	<input type="text"/>	^ T
E-Mail Address	<input type="text"/>	^ T

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Thank you for your time. It is truly appreciated

You are about to submit your answers for this survey. If you are ready to submit your answers, click "Submit". If you are not ready to submit your answers, click "Save only" to be able to return to the survey.

Submit Save only

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