

Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG of KIDS (CHSTRONG-KIDS)

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As explained in the letter you received with this survey, we are contacting you about this survey because our records show that your child was born with a heart problem. We would like to ask you some questions about your child’s heart problem.

The survey should be completed by a parent or adult caregiver who lives in this household and who is familiar with this child’s health and health care.

Please answer questions with information about your child with a heart problem only. **You may choose to skip any question you do not wish to answer.**

Child’s heart defect

1. What is the name of the heart problem that this child was born with? (Select 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
 - f. Ebstein anomaly
 - g. Hypoplastic left heart syndrome (HLHS)
 - h. Patent ductus arteriosus (PDA)
 - i. Pulmonary atresia
 - j. Pulmonary valve stenosis
 - k. Single ventricle (double inlet left ventricle)
 - l. Tetralogy of Fallot (TOF)
 - m. Transposition of the great arteries (TGA)
 - n. Tricuspid atresia
 - o. Truncus arteriosus
 - p. Ventricular septal defect (VSD)
 - q. Other, specify _____
 - r. Don’t know/not sure
 - s. No heart problem that I know of (***Please answer remaining questions to the best of your ability***)

2. Has this child ever had surgery for the heart problem they were born with?
 - a. Yes
 - b. No
 - c. Don't know/not sure

3. When this child was first diagnosed with a heart problem, do you feel like you were provided enough information about what this meant for this child?
 - a. Yes
 - b. No
 - c. Don't know/not sure

Child's information

4. In what month and year was this child born?

Month:

Year: _____

- a. January
 - b. February
 - c. March
 - d. April
 - e. May
 - f. June
 - g. July
 - h. August
 - i. September
 - j. October
 - k. November
 - l. December
-
5. Is this child Hispanic or Latino?
 - a. Hispanic or Latino
 - b. Not Hispanic or Latino

 6. What is this child's race? (Select all that apply)
 - a. American Indian or Alaska Native alone
 - b. Asian
 - c. Black or African American
 - d. Native Hawaiian or Other Pacific Islander
 - e. White

Child's general health

If this child is younger than 6 years old, skip to question 9.

7. What is this child's CURRENT height? **(Answer in either feet and inches or meters and centimeters)**
 - a. ___ Feet AND ___ inches
 - b. ___ Meters AND ___ centimeters

8. How much does this child CURRENTLY weigh? **(Answer in either pounds or kilograms)**
 - a. ___ Pounds
 - b. ___ Kilograms

9. In general, how would you describe this child's health?
 - a. Excellent
 - b. Very good
 - c. Good
 - d. Fair
 - e. Poor

Child's medical conditions

10. Has a doctor or other health care provider EVER told you that this child has...
 - a. Anxiety problems [Yes / No]
 - b. Depression [Yes / No]
 - c. Developmental delay [Yes / No]
 - d. Behavioral or conduct problems [Yes / No]
 - e. Intellectual disability (formerly known as Mental Retardation) [Yes / No]
 - f. Speech or other language disorder [Yes / No]
 - g. Learning disability [Yes / No]
 - h. Attention Deficit Disorder or Attention Deficit/Hyperactivity Disorder, that is, ADD or ADHD [Yes / No]
 - i. Autism, Autism Spectrum Disorder, Asperger's Disorder, or Pervasive Developmental Disorder (PDD) [Yes / No]
 - j. Diabetes [Yes / No]
 - k. Down Syndrome [Yes / No]
 - l. Other genetic or inherited condition [Yes / No]
 - m. Heart failure [Yes / No]
 - n. Cardiac dysrhythmias or irregular heartbeat [Yes / No]
 - o. Other (specify) [Yes/ No] _____

11. Does this child have any of the following?
 - a. Deafness or problems with hearing [Yes/No]

- b. Blindness or problems with seeing, even when wearing eyeglasses [Yes/No]
If this child is younger than 6 years old, skip to the next question (#12).
- c. Serious difficulty walking or climbing stairs - [Yes/No]

Special healthcare needs

- 12. Does this child CURRENTLY need or use medicine prescribed by a doctor, other than vitamins?
 - a. Yes
 - b. No

- 13. Does this child need or use more medical care, mental health, or educational services than is usual for most children of the same age?
 - a. Yes
 - b. No

- 14. Is this child limited or prevented in any way in their ability to do the things most children of the same age can do?
 - a. Yes
 - b. No – ***Skip to question 16***

- 15. To what extent do this child's health conditions or problems affect their ability to do things?
 - a. Very little
 - b. Somewhat
 - c. A great deal

- 16. Does this child need or get special therapy, such as physical, occupational, or speech therapy?
 - a. Yes
 - b. No

- 17. Does this child have any kind of emotional, developmental, or behavioral problem for which they need treatment or counseling?
 - a. Yes
 - b. No

- 18. If **YES** to any of questions above in this Special Healthcare Needs section (Questions 12-17), is it because of ANY medical, behavioral, or other health condition that is expected to last 12 months or longer?
 - a. Yes
 - b. No
 - c. All my responses to Questions 12-17 were NO

Child's school/learning history

If this child is younger than 3 years old, skip to question 39. If this child is between 3 and 5 years old, skip to question 27.

19. What grade is this child currently in? (If summer, what is the highest grade level this child has already completed)?
- Kindergarten
 - 1st grade
 - 2nd grade
 - 3rd grade
 - 4th grade
 - 5th grade
 - 6th grade
 - 7th grade
 - 8th grade
 - 9th grade
 - 10th grade
 - 11th grade
 - 12th grade
20. Since starting kindergarten, has this child repeated any grades?
- Yes
 - No
21. DURING THE PAST 12 MONTHS, about how many days did this child miss school because of illness or injury?
- No missed school days
 - 1-3 days
 - 4-6 days
 - 7-10 days
 - 11 or more days
 - This child was not enrolled in school
22. Has this child EVER had any of the following special education or early intervention plans?
(Select all that apply)
- Individualized Family Service Plan or IFSP (used for early intervention services in children younger than 3)
 - Individualized Education Plan or IEP (used for special education services in children 3 or older)
 - 504 Plan (sometimes used for special education services instead of or in addition to an IEP)
 - Other, specify _____

- e. No, this child has never had a plan for special education

If your child is younger than 12 years old, skip to question 24.

23. How likely do you think it is that this child will...

- a. Get a regular high school diploma? A regular high school diploma includes a “GED” but does not include a certificate of completion or a special diploma for students in special education

[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

- b. Attend school after high school? Including technical or trade school

[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

- c. Attend a special training program after high school for persons with intellectual disabilities?

[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has / Does not apply]

- d. Complete a technical or trade school program?

[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

- e. Graduate from a 2-year or community college?

[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

- f. Graduate from a 4-year college?

[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

- g. Get a driver's license?

[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

- h. Eventually live away from home on his or her own without supervision?

[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

- i. Eventually live away on his or her own with supervision?

[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

- j. Eventually get a paid job? This includes any paid job -- child does not need to make enough to support self. This can include sheltered or supported employment.

[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

- k. Earn enough to support himself or herself without financial help from his or her family or government benefit programs?

[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

Child's activities and social environment

24. DURING THE PAST WEEK, on how many days did this child exercise, play a sport, or participate in physical activity for at least 60 minutes?

- a. 0 days
- b. 1-3 days
- c. 4-6 days
- d. Every day

25. DURING THE PAST 12 MONTHS, did this child participate in:

- a. A sports team or did he or she take sports lessons after school or on weekends?
[Yes/No]
- b. Any clubs or organizations after school or on weekends? [Yes/No]
- c. Any other organized activities or lessons, such as music, dance, language, or other arts?
[Yes/No]
- d. Any type of community service or volunteer work at school, church, or in the community? [Yes/No]
- e. Any work, including regular jobs as well as babysitting, cutting grass, or other occasional work? [Yes/No]

26. DURING THE PAST 12 MONTHS, how often was this child bullied, picked on, or excluded by other children?

- a. Never
- b. 1-2 times (in the past 12 months)
- c. 1-2 times per month
- d. 1-2 times per week
- e. Almost every day

27. Compared to other children their age, how much difficulty does this child have making or keeping friends?
- a. No difficulty
 - b. A little difficulty
 - c. A lot of difficulty

Child's readiness to learn

Answer questions 28 - 38 only if this child is between 3 and 5 years old. Otherwise skip to question 39.

28. How often does this child share toys or games with other children?
- a. Always
 - b. Most of the time
 - c. About half of the time
 - d. Sometimes
 - e. Never
29. How often does this child show concern when they see others who are hurt or unhappy?
- a. Always
 - b. Most of the time
 - c. About half of the time
 - d. Sometimes
 - e. Never
30. How often does this child play well with other children?
- a. Always
 - b. Most of the time
 - c. About half of the time
 - d. Sometimes
 - e. Never
31. How often can this child recognize and name their own emotions?
- a. Always
 - b. Most of the time
 - c. About half of the time
 - d. Sometimes
 - e. Never
32. How often does this child have difficulty when asked to end one activity and start a new activity?
- a. Always
 - b. Most of the time

- c. About half of the time
- d. Sometimes
- e. Never

33. How often does this child lose their temper?

- a. Always
- b. Most of the time
- c. About half of the time
- d. Sometimes
- e. Never

34. How often does this child have trouble calming down?

- a. Always
- b. Most of the time
- c. About half of the time
- d. Sometimes
- e. Never

35. How often does this child have difficulty waiting for their turn?

- a. Always
- b. Most of the time
- c. About half of the time
- d. Sometimes
- e. Never

36. How often does this child get easily distracted?

- a. Always
- b. Most of the time
- c. About half of the time
- d. Sometimes
- e. Never

37. How often can this child focus on a task you have given them for at least a few minutes? For example, simple chores?

- a. Always
- b. Most of the time
- c. About half of the time
- d. Sometimes
- e. Never

38. How often does this child keep working at a task even when it is hard for them?

- a. Always
- b. Most of the time
- c. About half of the time

- d. Sometimes
- e. Never

Child's Health Care

39. Where does this child usually go when he or she is sick or you need advice about his or her health?
- a. This child does not have a usual place for health care or advice when sick
 - b. Doctor's Office
 - c. Hospital Emergency Room
 - d. Hospital Outpatient Department
 - e. Urgent Care Center
 - f. Clinic or Health Center
 - g. Retail Store Clinic or "Minute Clinic"
 - h. School (Nurse's Office, Athletic Trainer's Office)
 - i. Some other place
40. DURING THE PAST 12 MONTHS, how many times did this child visit a doctor, nurse, or other health care professional to receive a PREVENTIVE check-up? A preventive check-up is when this child was not sick or injured, such as an annual or sports physical, or well-child visit.
- a. 0 visits
 - b. 1 visit
 - c. 2 or more visits
41. DURING THE PAST 12 MONTHS, how many times did this child visit a hospital emergency room?
- a. None
 - b. 1 time
 - c. 2 or more times
42. DURING THE PAST 12 MONTHS, was this child admitted to the hospital to stay for at least one night?
- a. Yes
 - b. No

Child's Heart Doctors

43. When is the last time this child saw a heart doctor?
- a. Less than 1 year
 - b. 1-2 years
 - c. 3-5 years - **Skip to question 48**
 - d. More than 5 years - **Skip to question 48**
 - e. Never seen one - **Skip to question 48**

44. How many health care provider visits were with a heart doctor or at a cardiology clinic (clinic that only sees patients with heart problems) in the past 12 months?
- ____ Numeric response
45. Who are the majority of patients that this child's primary heart doctor usually sees?
- Children and adolescents (pediatric cardiologist)
 - Adults (adult congenital heart cardiologist or adult cardiologist) - **Skip to question 47**
 - Don't know/not sure
46. Has a doctor or other health care provider talked with you about when this child will need to see heart doctors who treat adults?
- Yes
 - No
47. In the past 2 years, how often has this child's heart doctor
- Spent enough time with this child? [Always/Usually/Sometimes/Never]
 - Listened carefully to you? [Always/Usually/Sometimes/Never]
 - Shown sensitivity to your family's values and customs? [Always/Usually/Sometimes/Never]
 - Provided the specific information you needed concerning this child? [Always/Usually/Sometimes/Never]
 - Helped you feel like a partner in this child's care? [Always/Usually/Sometimes/Never]
 - Discussed with you the range of options to consider for their health care or treatment? [Always/Usually/Sometimes/Never]
 - Made it easy for you to raise concerns or disagree with recommendations for this child's health care? [Always/Usually/Sometimes/Never]
 - Worked with you to decide together which health care and treatment choices would be best for this child? [Always/Usually/Sometimes/Never] - **Skip to question 49**
48. If this child has not seen a heart doctor in the last 2 years or ever, why? (Select all that apply)
- This child felt well
 - Did not think this child needed to see a heart doctor
 - Doctor told me this child no longer needed to see a heart doctor
 - Changed or lost insurance
 - Moved to a different city or town
 - Did not like this child's heart doctor
 - Couldn't find a heart doctor
 - I had too many other things going on
 - There were issues related to cost
 - I chose to postpone or cancel appointments due to COVID
 - This child's heart doctor postponed or cancelled appointments due to COVID
 - Other

Unmet Needs

49. DURING THE PAST 12 MONTHS, did this child need any of the following health care but it was not received? (Select all that apply)
- Heart care
 - Other medical care
 - Dental care
 - Vision care
 - Hearing care
 - Mental health services
 - Other, specify _____
 - This child has received all the healthcare they needed in the past 12 months - **Skip to question 51**
50. Did any of the following reasons contribute to this child not receiving needed health services?
- This child did not have health insurance that covered the services needed [Yes / No]
 - This child was not eligible for the services [Yes / No]
 - The services this child needed were not available in your area [Yes / No]
 - There were problems getting an appointment when this child needed one [Yes / No]
 - There were problems with getting transportation or child care [Yes / No]
 - I had too many other things going on [Yes / No]
 - The clinic or doctor's office wasn't open when this child needed care [Yes / No]
 - There were issues related to cost [Yes / No]
 - I chose to postpone or cancel appointments due to COVID [Yes / No]
 - The clinic or doctor's office postponed or cancelled appointments due to COVID [Yes / No]
 - Other, specify [Yes / No] _____

Child's insurance

51. Is this child CURRENTLY covered by ANY kind of health insurance or health coverage plan?
- Yes
 - No - **If this child is at least 12 years old, skip to question 53. Otherwise skip to question 59.**
52. Is this child CURRENTLY covered by any of the following types of health insurance or health coverage plans?
- Insurance through a current or former employer or union [Yes/No]
 - Insurance purchased directly from an insurance company, including the Health Insurance Marketplace from the Affordable Care Act (ACA) [Yes/No]
 - Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or a disability [Yes/No]
 - TRICARE or other military health care [Yes/No]
 - Indian Health Service [Yes/No]

- f. Other, specify [Yes/No] _____

Transition to adult healthcare

Answer questions 53-58 only if this child is at least 12 years old. Otherwise skip to question 59.

53. Eligibility for health insurance often changes in young adulthood. Do you know how this child will be insured as he/she becomes an adult?
- Yes – **Skip to question 55**
 - No
54. If no, has anyone discussed with you how to obtain or keep some type of health insurance coverage as this child becomes an adult?
- Yes
 - No
55. Has a doctor or other health care provider ever discussed with you this child's need to see a heart doctor throughout their life?
- Yes
 - No
56. Has this child's doctor or other health care provider actively worked with the child to:
- Make positive choices about his/her health? For example, by eating healthy, getting regular exercise, not using tobacco, alcohol or other drugs, or delaying sexual activity

[Yes / No / Don't know]
 - Gain skills to manage his/her health and health care? For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications he/she may need

[Yes / No / Don't know]
 - Understand the changes in health care that happen at age 18? For example, by understanding changes in privacy, consent, access to information, or decision-making

[Yes / No / Don't know]
57. How prepared do you feel this child is to make positive choices about his/her health, manage his/her own health and health care, and handle changes in health care that happen at age 18?
- Very prepared
 - Somewhat prepared
 - Not very prepared

- d. Not at all prepared
58. Have this child's doctors or other health care providers worked with you and this child to create a plan of care to meet their health goals and needs?
- a. Yes
 - b. No
59. Please rate how concerned you are about this child's future health
- a. Very concerned
 - b. Somewhat concerned
 - c. Not very concerned
 - d. Not at all concerned

Immunizations

60. DURING THE PAST 12 MONTHS, has this child had a flu vaccination? A flu vaccination is usually given in the fall and protects against influenza for the flu season.
- a. Yes
 - b. No

COVID-19

61. Has this child ever had coronavirus or COVID-19 (based on a positive test for COVID-19 or a health professional telling you the child had COVID-19)?
- a. Yes
 - b. No
 - c. Did not receive results
62. Please select the statement that best describes this child regarding the COVID-19 vaccine:
- a. This child has received at least two doses of vaccine for COVID-19 - ***Skip to question 64***
 - b. This child has received one dose of vaccine, and I intend for them to receive a second dose - ***Skip to question 64***
 - c. This child has received one dose of vaccine, and I do not intend for them to receive a second dose
 - d. This child has not received any vaccine for COVID-19
 - e. Other
63. What are your reasons for choosing not to get this child fully vaccinated? (Select all that apply)
- a. I'm concerned about the potential side effects of the vaccine
 - b. I feel the vaccines were created too quickly
 - c. I don't believe the vaccines are effective at preventing the spread of COVID-19
 - d. I'm not concerned about this child contracting COVID-19
 - e. I'm generally opposed to vaccinations
 - f. A friend or family member had a bad reaction to the vaccine

- g. I don't think that a vaccine is necessary because COVID-19 is not a serious threat
- h. This child's doctor advised me not to get this child vaccinated
- i. Other, specify _____
- j. I prefer not to say

Caregiver information

64. How are you related to this child?
- a. Biological or adoptive parent
 - b. Step-parent
 - c. Grandparent
 - d. Foster parent
 - e. Other: Relative
 - f. Other: Non-relative
65. What is your age in years?
- a. ____ Numeric response
66. What is your marital status?
- a. Married
 - b. Not married, but living with partner
 - c. Never married
 - d. Divorced
 - e. Separated
 - f. Widowed
67. What is the highest grade or level of school you have completed?
- a. 8th grade or less
 - b. 9th-12th grade; No diploma
 - c. High School Graduate or GED Completed
 - d. Completed a vocational, trade, or business school program
 - e. Some College Credit, but no Degree
 - f. Associate Degree (AA, AS)
 - g. Bachelor's Degree (BA, BS, AB)
 - h. Master's Degree (MA, MS, MSW, MBA)
 - i. Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)
68. Which of the following best describes your current employment status?
- a. Employed full time
 - b. Employed part-time
 - c. Working WITHOUT pay
 - d. Not employed but looking for work
 - e. Not employed and not looking for work

69. Does this child have another parent or adult caregiver who lives in this household?
- Yes
 - No - **Skip to Question 73**
70. How is this other caregiver related to this child?
- Biological or adoptive parent
 - Step-parent
 - Grandparent
 - Foster parent
 - Other: Relative
 - Other: Non-relative
71. What is the highest grade or level of school this caregiver has completed?
- 8th grade or less
 - 9th-12th grade; No diploma
 - High School Graduate or GED Completed
 - Completed a vocational, trade, or business school program
 - Some College Credit, but no Degree
 - Associate Degree (AA, AS)
 - Bachelor's Degree (BA, BS, AB)
 - Master's Degree (MA, MS, MSW, MBA)
 - Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)
72. Which of the following best describes this caregiver's current employment status?
- Employed full time
 - Employed part-time
 - Working WITHOUT pay
 - Not employed but looking for work
 - Not employed and not looking for work
73. How many children under the age of 18 are now living in the household, **not including this child**?
- ____ Numeric response

Caregiver burden

74. In general, how is your mental or emotional health?
- Excellent
 - Very good
 - Good
 - Fair
 - Poor

75. How well do you feel that you are handling the day-to-day demands of raising a child with a heart problem?
- Very well
 - Somewhat well
 - Not very well
 - Not well at all
76. DURING THE PAST 12 MONTHS, was there someone that you could turn to for day-to-day emotional support with parenting or raising a child with a heart problem?
- Yes
 - No - **Skip to Question 78**
77. If yes, did you receive support from:
- Spouse or domestic partner? [Yes / No]
 - Other family member or close friend? [Yes / No]
 - Health care provider? [Yes / No]
 - Place of worship or religious leader? [Yes / No]
 - Support or advocacy group related to specific health condition? [Yes / No]
 - Peer support group? [Yes / No]
 - Counselor or other mental health professional? [Yes / No]
 - Other person, specify [Yes / No] _____
78. DURING THE PAST 12 MONTHS, did your family have problems paying for any of this child's medical or health care bills?
- Yes
 - No
79. DURING THE PAST 12 MONTHS, have you or other family members...
- Left a job or taken a leave of absence because of this child's health or health conditions? [Yes/No]
 - Cut down on the hours you work because of this child's health or health conditions? [Yes/No]
 - Avoided changing jobs because of concerns about maintaining health insurance for this child? [Yes/No]
80. IN AN AVERAGE WEEK, how many hours do you or other family members spend providing health care at home for this child? *Care might include changing bandages or giving medication and therapies when needed.*
- This child does not need health care provided at home on a weekly basis
 - Less than 1 hour per week
 - 1-4 hours per week
 - 5-10 hours per week
 - 11 or more hours per week

81. At any time DURING THE PAST 12 MONTHS, even for one month, did anyone in your family receive:
- Cash assistance from a government welfare program? [Yes / No]
 - Food stamps or Supplemental Nutrition Assistance Program (SNAP) benefits? [Yes / No]
 - Free or reduced-cost breakfast or lunches at school? [Yes / No]
 - Benefits from the Women, Infants, and Children (WIC) program? [Yes / No]
82. SINCE THIS CHILD WAS BORN, how often has it been very hard to cover the basics, like food or housing, on your family's income?
- Never
 - Rarely
 - Somewhat often
 - Very often

Adverse Childhood Experiences (ACEs)

The next questions are about events that may have happened during this child's life. These things can happen in any family, but some people may feel uncomfortable with these questions. As a reminder, you may skip any questions you do not want to answer.

83. To the best of your knowledge, has this child EVER experienced any of the following?
- Parent or guardian divorced or separated [Yes / No]
 - Parent or guardian died [Yes / No]
 - Parent or guardian served time in jail or prison [Yes / No]
 - Saw or heard parents or adults slap, hit, kick, or punch one another in the home [Yes / No]
 - Was a victim of violence or witnessed violence in their neighborhood [Yes / No]
 - Lived with anyone who was mentally ill, suicidal, or severely depressed [Yes / No]
 - Lived with anyone who had a problem with alcohol or drugs [Yes / No]
 - Treated or judged unfairly because of his or her race or ethnic group [Yes / No]
 - Treated or judged unfairly because of a health condition or disability [Yes / No]
- If child is younger than 6, skip to next question (#84).***
- Treated or judged unfairly because of their sexual orientation or gender identity [Yes / No]

Future Needs

84. What is the biggest concern you have about this child's future?
- [Free text response]
85. What type of information or help do you think should be available to children born with heart problems and their caregivers?
- [Free text response]

Contact Information

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