#### Form Approved

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#### 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)
   1. Aortic valve stenosis
   2. Atrial septal defect (ASD)
   3. Atrioventricular septal defect (AVSD) or Atrioventricular canal (AV canal)
   4. Bicuspid aortic valve
   5. Coarctation of aorta
   6. Ebstein anomaly
   7. Hypoplastic left heart syndrome (HLHS)
   8. Patent ductus arteriosus (PDA)
   9. Pulmonary atresia
   10. Pulmonary valve stenosis
   11. Single ventricle (double inlet left ventricle)
   12. Tetralogy of Fallot (TOF)
   13. Transposition of the great arteries (TGA)
   14. Tricuspid atresia
   15. Truncus arteriosus
   16. Ventricular septal defect (VSD)
   17. Other, specify \_\_\_\_\_\_\_\_\_\_\_\_\_
   18. Don’t know/not sure
   19. 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?
   1. Yes
   2. No
   3. 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?
   1. Yes
   2. No
   3. Don’t know/not sure

## Child’s information

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

Month:

Year: \_\_\_\_\_\_\_\_\_\_\_\_

* 1. January
  2. February
  3. March
  4. April
  5. May
  6. June
  7. July
  8. August
  9. September
  10. October
  11. November
  12. December

1. Is this child Hispanic or Latino?
   1. Hispanic or Latino
   2. Not Hispanic or Latino
2. What is this child’s race? (Select all that apply)
3. American Indian or Alaska Native alone
4. Asian
5. Black or African American
6. Native Hawaiian or Other Pacific Islander
7. White

## Child’s general health

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

1. What is this child’s CURRENT height? ***(Answer in either feet and inches or meters and centimeters)***
2. ­­­\_\_\_ Feet AND \_\_\_ inches
3. \_\_\_ Meters AND \_\_\_ centimeters
4. How much does this child CURRENTLY weigh? ***(Answer in either pounds or kilograms)***
   1. \_\_\_ Pounds
   2. \_\_\_ Kilograms
5. In general, how would you describe this child's health?
6. Excellent
7. Very good
8. Good
9. Fair
10. Poor

## Child’s medical conditions

1. Has a doctor or other health care provider EVER told you that this child has…
2. Anxiety problems [Yes / No]
3. Depression [Yes / No]
4. Developmental delay [Yes / No]
5. Behavioral or conduct problems [Yes / No]
6. Intellectual disability (formerly known as Mental Retardation) [Yes / No]
7. Speech or other language disorder [Yes / No]
8. Learning disability [Yes / No]
9. Attention Deficit Disorder or Attention Deficit/Hyperactivity Disorder, that is, ADD or ADHD [Yes / No]
10. Autism, Autism Spectrum Disorder, Asperger’s Disorder, or Pervasive Developmental Disorder (PDD) [Yes / No]
11. Diabetes [Yes / No]
12. Down Syndrome [Yes / No]
13. Other genetic or inherited condition [Yes / No]
14. Heart failure [Yes / No]
15. Cardiac dysrhythmias or irregular heartbeat [Yes / No]
16. Other (specify) [Yes/ No] \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
17. Does this child have any of the following?
    1. Deafness or problems with hearing [Yes/No]
    2. 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).***

* 1. Serious difficulty walking or climbing stairs - [Yes/No]

## Special healthcare needs

1. Does this child CURRENTLY need or use medicine prescribed by a doctor, other than vitamins?
2. Yes
3. No
4. Does this child need or use more medical care, mental health, or educational services than is usual for most children of the same age?
5. Yes
6. No
7. Is this child limited or prevented in any way in their ability to do the things most children of the same age can do?
8. Yes
9. No – ***Skip to question 16***
10. To what extent do this child’s health conditions or problems affect their ability to do things?
11. Very little
12. Somewhat
13. A great deal
14. Does this child need or get special therapy, such as physical, occupational, or speech therapy?
15. Yes
16. No
17. Does this child have any kind of emotional, developmental, or behavioral problem for which they need treatment or counseling?
18. Yes
19. No
20. 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?
21. Yes
22. No
23. 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.***

1. What grade is this child currently in? (If summer, what is the highest grade level this child has already completed)?
2. Kindergarten
3. 1st grade
4. 2nd grade
5. 3rd grade
6. 4th grade
7. 5th grade
8. 6th grade
9. 7th grade
10. 8th grade
11. 9th grade
12. 10th grade
13. 11th grade
14. 12th grade
15. Since starting kindergarten, has this child repeated any grades?
16. Yes
17. No
18. DURING THE PAST 12 MONTHS, about how many days did this child miss school because of illness or injury?
19. No missed school days
20. 1-3 days
21. 4-6 days
22. 7-10 days
23. 11 or more days
24. This child was not enrolled in school
25. Has this child EVER had any of the following special education or early intervention plans? (Select all that apply)
26. Individualized Family Service Plan or IFSP (used for early intervention services in children younger than 3)
27. Individualized Education Plan or IEP (used for special education services in children 3 or older)
28. 504 Plan (sometimes used for special education services instead of or in addition to an IEP)
29. Other, specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
30. No, this child has never had a plan for special education

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

1. How likely do you think it is that this child will…
2. 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]

1. 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]

1. 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]

1. Complete a technical or trade school program?

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

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

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

1. Graduate from a 4-year college?

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

1. Get a driver’s license?

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

1. 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]

1. 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]

1. 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]

1. 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

1. 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?
2. 0 days
3. 1-3 days
4. 4-6 days
5. Every day
6. DURING THE PAST 12 MONTHS, did this child participate in:
7. A sports team or did he or she take sports lessons after school or on weekends? [Yes/No]
8. Any clubs or organizations after school or on weekends? [Yes/No]
9. Any other organized activities or lessons, such as music, dance, language, or other arts? [Yes/No]
10. Any type of community service or volunteer work at school, church, or in the community? [Yes/No]
11. Any work, including regular jobs as well as babysitting, cutting grass, or other occasional work? [Yes/No]
12. DURING THE PAST 12 MONTHS, how often was this child bullied, picked on, or excluded by other children?
13. Never
14. 1-2 times (in the past 12 months)
15. 1-2 times per month
16. 1-2 times per week
17. Almost every day
18. Compared to other children their age, how much difficulty does this child have making or keeping friends?
19. No difficulty
20. A little difficulty
21. 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.***

1. How often does this child share toys or games with other children?
   1. Always
   2. Most of the time
   3. About half of the time
   4. Sometimes
   5. Never
2. How often does this child show concern when they see others who are hurt or unhappy?
   1. Always
   2. Most of the time
   3. About half of the time
   4. Sometimes
   5. Never
3. How often does this child play well with other children?
   1. Always
   2. Most of the time
   3. About half of the time
   4. Sometimes
   5. Never
4. How often can this child recognize and name their own emotions?
   1. Always
   2. Most of the time
   3. About half of the time
   4. Sometimes
   5. Never
5. How often does this child have difficulty when asked to end one activity and start a new activity?
   1. Always
   2. Most of the time
   3. About half of the time
   4. Sometimes
   5. Never
6. How often does this child lose their temper?
   1. Always
   2. Most of the time
   3. About half of the time
   4. Sometimes
   5. Never
7. How often does this child have trouble calming down?
   1. Always
   2. Most of the time
   3. About half of the time
   4. Sometimes
   5. Never
8. How often does this child have difficulty waiting for their turn?
   1. Always
   2. Most of the time
   3. About half of the time
   4. Sometimes
   5. Never
9. How often does this child get easily distracted?
   1. Always
   2. Most of the time
   3. About half of the time
   4. Sometimes
   5. Never
10. How often can this child focus on a task you have given them for at least a few minutes? For example, simple chores?
    1. Always
    2. Most of the time
    3. About half of the time
    4. Sometimes
    5. Never
11. How often does this child keep working at a task even when it is hard for them?
    1. Always
    2. Most of the time
    3. About half of the time
    4. Sometimes
    5. Never

## Child’s Health Care

1. Where does this child usually go when he or she is sick or you need advice about his or her health?
   1. This child does not have a usual place for health care or advice when sick
   2. Doctor's Office
   3. Hospital Emergency Room
   4. Hospital Outpatient Department
   5. Urgent Care Center
   6. Clinic or Health Center
   7. Retail Store Clinic or "Minute Clinic"
   8. School (Nurse's Office, Athletic Trainer's Office)
   9. Some other place
2. 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.
3. 0 visits
4. 1 visit
5. 2 or more visits
6. DURING THE PAST 12 MONTHS, how many times did this child visit a hospital emergency room?
7. None
8. 1 time
9. 2 or more times
10. DURING THE PAST 12 MONTHS, was this child admitted to the hospital to stay for at least one night?
11. Yes
12. No

## Child’s Heart Doctors

1. When is the last time this child saw a heart doctor?
2. Less than 1 year
3. 1-2 years
4. 3-5 years - ***Skip to question 48***
5. More than 5 years - ***Skip to question 48***
6. Never seen one - ***Skip to question 48***
7. 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?
8. \_ \_ \_ Numeric response
9. Who are the majority of patients that this child’s primary heart doctor usually sees?
10. Children and adolescents (pediatric cardiologist)
11. Adults (adult congenital heart cardiologist or adult cardiologist) - ***Skip to question 47***
12. Don’t know/not sure
13. Has a doctor or other health care provider talked with you about when this child will need to see heart doctors who treat adults?
14. Yes
15. No
16. In the past 2 years, how often has this child’s heart doctor
    1. Spent enough time with this child? [Always/Usually/Sometimes/Never]
    2. Listened carefully to you? [Always/Usually/Sometimes/Never]
    3. Shown sensitivity to your family’s values and customs? [Always/Usually/Sometimes/Never]
    4. Provided the specific information you needed concerning this child? [Always/Usually/Sometimes/Never]
    5. Helped you feel like a partner in this child’s care? [Always/Usually/Sometimes/Never]
    6. Discussed with you the range of options to consider for their health care or treatment? [Always/Usually/Sometimes/Never]
    7. Made it easy for you to raise concerns or disagree with recommendations for this child’s health care? [Always/Usually/Sometimes/Never]
    8. 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***
17. If this child has not seen a heart doctor in the last 2 years or ever, why? (Select all that apply)
18. This child felt well
19. Did not think this child needed to see a heart doctor
20. Doctor told me this child no longer needed to see a heart doctor
21. Changed or lost insurance
22. Moved to a different city or town
23. Did not like this child’s heart doctor
24. Couldn't find a heart doctor
25. I had too many other things going on
26. There were issues related to cost
27. I chose to postpone or cancel appointments due to COVID
28. This child’s heart doctor postponed or cancelled appointments due to COVID
29. Other

## Unmet Needs

1. DURING THE PAST 12 MONTHS, did this child need any of the following health care but it was not received? (Select all that apply)
2. Heart care
3. Other medical care
4. Dental care
5. Vision care
6. Hearing care
7. Mental health services
8. Other, specify \_\_\_\_\_\_\_\_\_\_\_\_\_
9. This child has received all the healthcare they needed in the past 12 months - ***Skip to question 51***
10. Did any of the following reasons contribute to this child not receiving needed health services?
11. This child did not have health insurance that covered the services needed [Yes / No]
12. This child was not eligible for the services [Yes / No]
13. The services this child needed were not available in your area [Yes / No]
14. There were problems getting an appointment when this child needed one [Yes / No]
15. There were problems with getting transportation or child care [Yes / No]
16. I had too many other things going on [Yes / No]
17. The clinic or doctor’s office wasn’t open when this child needed care [Yes / No]
18. There were issues related to cost [Yes / No]
19. I chose to postpone or cancel appointments due to COVID [Yes / No]
20. The clinic or doctor’s office postponed or cancelled appointments due to COVID [Yes / No]
21. Other, specify [Yes / No] \_\_\_\_\_\_\_\_\_\_\_\_\_

Child’s insurance

1. Is this child CURRENTLY covered by ANY kind of health insurance or health coverage plan?
   1. Yes
   2. No - ***If this child is at least 12 years old, skip to question 53. Otherwise skip to question 59.***
2. Is this child CURRENTLY covered by any of the following types of health insurance or health coverage plans?
   1. Insurance through a current or former employer or union [Yes/No]
   2. Insurance purchased directly from an insurance company, including the Health Insurance Marketplace from the Affordable Care Act (ACA) [Yes/No]
   3. Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or a disability [Yes/No]
   4. TRICARE or other military health care [Yes/No]
   5. Indian Health Service [Yes/No]
   6. 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.***

1. Eligibility for health insurance often changes in young adulthood. Do you know how this child will be insured as he/she becomes an adult?
2. Yes – **Skip to question 55**
3. No
4. If no, has anyone discussed with you how to obtain or keep some type of health insurance coverage as this child becomes an adult?
   1. Yes
   2. No
5. Has a doctor or other health care provider ever discussed with you this child’s need to see a heart doctor throughout their life?
6. Yes
7. No
8. Has this child’s doctor or other health care provider actively worked with the child to:
9. 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]

1. 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]

1. 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]

1. 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?
   1. Very prepared
   2. Somewhat prepared
   3. Not very prepared
   4. Not at all prepared
2. 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?
   1. Yes
   2. No
3. Please rate how concerned you are about this child’s future health
   1. Very concerned
   2. Somewhat concerned
   3. Not very concerned
   4. Not at all concerned

## Immunizations

1. 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.
   1. Yes
   2. No

## COVID-19

1. 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)?
2. Yes
3. No
4. Did not receive results
5. Please select the statement that best describes this child regarding the COVID-19 vaccine:
6. This child has received at least two doses of vaccine for COVID-19 - ***Skip to question 64***
7. This child has received one dose of vaccine, and I intend for them to receive a second dose - ***Skip to question 64***
8. This child has received one dose of vaccine, and I do not intend for them to receive a second dose
9. This child has not received any vaccine for COVID-19
10. Other
11. What are your reasons for choosing not to get this child fully vaccinated? (Select all that apply)
12. I’m concerned about the potential side effects of the vaccine
13. I feel the vaccines were created too quickly
14. I don’t believe the vaccines are effective at preventing the spread of COVID-19
15. I’m not concerned about this child contracting COVID-19
16. I’m generally opposed to vaccinations
17. A friend or family member had a bad reaction to the vaccine
18. I don’t think that a vaccine is necessary because COVID-19 is not a serious threat
19. This child’s doctor advised me not to get this child vaccinated
20. Other, specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
21. I prefer not to say

## Caregiver information

1. How are you related to this child?
2. Biological or adoptive parent
3. Step-parent
4. Grandparent
5. Foster parent
6. Other: Relative
7. Other: Non-relative
8. What is your age in years?
   1. \_ \_ \_ Numeric response
9. What is your marital status?
10. Married
11. Not married, but living with partner
12. Never married
13. Divorced
14. Separated
15. Widowed
16. What is the highest grade or level of school you have completed?
    1. 8th grade or less
    2. 9th-12th grade; No diploma
    3. High School Graduate or GED Completed
    4. Completed a vocational, trade, or business school program
    5. Some College Credit, but no Degree
    6. Associate Degree (AA, AS)
    7. Bachelor’s Degree (BA, BS, AB)
    8. Master’s Degree (MA, MS, MSW, MBA)
    9. Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)
17. Which of the following best describes your current employment status?
18. Employed full time
19. Employed part-time
20. Working WITHOUT pay
21. Not employed but looking for work
22. Not employed and not looking for work
23. Does this child have another parent or adult caregiver who lives in this household?
24. Yes
25. No - ***Skip to Question 73***
26. How is this other caregiver related to this child?
27. Biological or adoptive parent
28. Step-parent
29. Grandparent
30. Foster parent
31. Other: Relative
32. Other: Non-relative
33. What is the highest grade or level of school this caregiver has completed?
    1. 8th grade or less
    2. 9th-12th grade; No diploma
    3. High School Graduate or GED Completed
    4. Completed a vocational, trade, or business school program
    5. Some College Credit, but no Degree
    6. Associate Degree (AA, AS)
    7. Bachelor’s Degree (BA, BS, AB)
    8. Master’s Degree (MA, MS, MSW, MBA)
    9. Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)
34. Which of the following best describes this caregiver’s current employment status?
    1. Employed full time
    2. Employed part-time
    3. Working WITHOUT pay
    4. Not employed but looking for work
    5. Not employed and not looking for work
35. How many children under the age of 18 are now living in the household, **not including this child**?
36. \_ \_ \_ Numeric response

## Caregiver burden

1. In general, how is your mental or emotional health?
2. Excellent
3. Very good
4. Good
5. Fair
6. Poor
7. How well do you feel that you are handling the day-to-day demands of raising a child with a heart problem?
8. Very well
9. Somewhat well
10. Not very well
11. Not well at all
12. 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?
13. Yes
14. No– **Skip to Question 78**
15. If yes, did you receive support from:
16. Spouse or domestic partner? [Yes / No]
17. Other family member or close friend? [Yes / No]
18. Health care provider? [Yes / No]
19. Place of worship or religious leader? [Yes / No]
20. Support or advocacy group related to specific health condition? [Yes / No]
21. Peer support group? [Yes / No]
22. Counselor or other mental health professional? [Yes / No]
23. Other person, specify [Yes / No] \_\_\_\_\_\_\_\_\_\_\_\_\_
24. DURING THE PAST 12 MONTHS, did your family have problems paying for any of this child’s medical or health care bills?
    1. Yes
    2. No
25. DURING THE PAST 12 MONTHS, have you or other family members…
26. Left a job or taken a leave of absence because of this child’s health or health conditions? [Yes/No]
27. Cut down on the hours you work because of this child’s health or health conditions? [Yes/No]
28. Avoided changing jobs because of concerns about maintaining health insurance for this child? [Yes/No]
29. 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.*
30. This child does not need health care provided at home on a weekly basis
31. Less than 1 hour per week
32. 1-4 hours per week
33. 5-10 hours per week
34. 11 or more hours per week
35. At any time DURING THE PAST 12 MONTHS, even for one month, did anyone in your family receive:
36. Cash assistance from a government welfare program? [Yes / No]
37. Food stamps or Supplemental Nutrition Assistance Program (SNAP) benefits? [Yes / No]
38. Free or reduced-cost breakfast or lunches at school? [Yes / No]
39. Benefits from the Women, Infants, and Children (WIC) program? [Yes / No]
40. 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?
    1. Never
    2. Rarely
    3. Somewhat often
    4. 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.

1. To the best of your knowledge, has this child EVER experienced any of the following?
2. Parent or guardian divorced or separated [Yes / No]
3. Parent or guardian died [Yes / No]
4. Parent or guardian served time in jail or prison [Yes / No]
5. Saw or heard parents or adults slap, hit, kick, or punch one another in the home [Yes / No]
6. Was a victim of violence or witnessed violence in their neighborhood [Yes / No]
7. Lived with anyone who was mentally ill, suicidal, or severely depressed [Yes / No]
8. Lived with anyone who had a problem with alcohol or drugs [Yes / No]
9. Treated or judged unfairly because of his or her race or ethnic group [Yes / No]
10. Treated or judged unfairly because of a health condition or disability [Yes / No]

***If child is younger than 6, skip to next question (#84).***

1. Treated or judged unfairly because of their sexual orientation or gender identity [Yes / No]

## Future Needs

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

## Contact Information

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