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| Appendix A |
| **Check the box that best describes your heart condition. You may check more than one box or describe his/her condition under “other”** |
| * Aortic dilation
* Aortic stenosis
* Aortic incompetence/regurgitation
* Atrial septal defect
* Atrioventricular septal defect (total or partial)
* Bicuspid aortic valve
* Cardiac transplant
* Coarctation of the aorta
* Arrhythmogenic right ventricular cardiomyopathy
* Dilated cardiomyopathy
* Hypertrophic cardiomyopathy
* Restrictive cardiomyopathy
* Left ventricular noncompaction
* Double inlet left ventricle
* Double outlet right ventricle
 | * Heterotaxy syndrome
* Hypoplastic left heart (aortic atresia or mitral atresia)
* Hypoplastic right heart (tricuspid atresia, pulmonary atresia with an intact ventricular septum, or Ebstein’s anomaly)
* Interrupted aortic arch (Type A-C, unknown)
* Mitral valve prolapse
* Patent foramen ovale
* Patent ductus arteriosus
* Pulmonary atresia and ventricular septal defect
* Pulmonic stenosis
* Pulmonic incompetence
* Rhythm disturbance
* Single ventricle
* Supravalvar aortic stenosis
 | * Tetralogy of Fallot (pulmonary atresia and absent pulmonary valve)
* Total anomalous pulmonary venous connection/partial anomalous venous connection
* Transposition of the great arteries— d-TGA or l-TGA
* Truncus arteriosis
* Ventricular septal defect
* Down syndrome
* 22q11.2 deletion syndrome (Velocardiofacial syndrome; DiGeorge syndrome)
* Marfan syndrome
* Noonan syndrome
* Turner syndrome
* Williams syndrome
* Other Genetic Condition
 |
| **Were you able to answer question 2 (what is your heart condition) without assistance? (Child Only)** |
| Yes | No | Other |
| **Are you male or female? (Child Only) or Relationship to Child: (Parent Only)** |
| Male (Father) | Female (Mother) | Other |
| **How old are you? (Child Only)** |
| Free response (\_\_\_\_\_\_ years) |
| **What is your ethnicity?** |
| White | Asian | African American or Black | Native American or Pacific Islander | Hispanic | Other |
| **What grade are you/ is your child in?** |
| 7th | 8th | 9th | 10th | 11th | 12th and over |
| **Have you ever talked to your child/has anyone talked to you about the potential causes of their/your heart condition?** |
| Yes | No | Other |
| **Have any of your science classes in school covered topics in genetics? (Child Only)** |
| Yes | No | Other |
| **Does anyone else in your family have a similar condition?** |
| Yes | No | Other |
| **I believe my heart/my child’s condition is genetic** |
| Strongly agree | Agree | Neutral | Disagree | Strongly disagree |
| **What do you believe is the likelihood you/your child will pass on your/their heart condition onto potential children?** |
| No chance | Very little chance | Unsure | Some chance | Very good chance |
| **How often do you think about your/your child’s heart condition?** |
| Never | Rarely | Sometimes | Most of the time | Always |
| **I feel like I have a good understanding of my/my child’s heart condition** |
| Strongly agree | Agree | Neutral | Disagree | Strongly disagree |
| **Would you be interested in learning more about the genetics of your/your child’s heart condition?** |
| Yes | No | Other |
| **When do you think would be the best time (for your child) to receive genetic information about your/their heart condition?**  |
| 10-11 years | 12-13 years | 14-15 years | 16-17 years | 18-19 years | 20+ years |
| **If a health professional was to discuss the genetic information about your heart condition with you/your child now, how well do you think you/they would understand?** |
| I would have a hard time understanding conversations about my heart condition | I could retain parts of the discussion about my heart condition and would not ask questions with the health provider | I could retain parts of the discussion about my heart condition and would be comfortable asking questions of the health provider | I would fully understand my heart condition and would discuss my questions about my heart condition with the health provider |
| **What do you think would be the best way for you/your child to be educated on the genetic contribution to your/their heart condition? How would you most like to be educated on your heart condition?** |
| Handout/Brochure | Webpage/Social Media | In person | Other |
| **(17) Who do you think would be the best person for you/them to discuss this information with? Who would you most like to talk to about this information?** |
| Parent/Guardian | Friend | Doctor | Teacher | Other |