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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 | |