Introduction Letter

October 20, 2023

Parent or Guardian of «firstname» «lastname» «address1» «address2» «city», «state» «zip»

Dear Parent or Guardian of «firstname»,

Soon you will receive a packet in the mail containing information about the Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG of KIDS (CHSTRONG-KIDS), as well as a survey and gift card. Because your child was identified by the Massachusetts Department of Public Health Birth Defects Registry as a person born with a heart condition, we would like you to complete the short survey about your child, their quality of life, and access to healthcare. Your information will help us identify unmet needs of children born with heart conditions. CHSTRONG-KIDS is being conducted by Boston University School of Public Health in partnership with the Massachusetts Department of Public Health and Centers for Disease Control and Prevention (CDC). To learn more about this project, you can visit <<u>website address></u>.

The survey will take about 20 minutes. It can be completed online, by mail, or over the telephone. None of your answers will be linked to your name or your child's name. Your name and your child's name will never be released as having a heart condition, having completed the survey, or having been asked to participate. We know your time is valuable. As a thank you, we will include a \$5.00 gift card for you to keep whether or not you complete the survey. If you choose to complete the survey, we will send you another gift card worth \$20.00 to thank you for the additional time and effort spent.

Please return the included postcard if you prefer not to be contacted again and we will remove you from the survey.

Across the country, thousands of parents and caregivers of children born with heart conditions are taking part in this survey. Everyone's answers are important to us and will add to what we learn about how heart conditions affect children. The findings from the survey may help identify unmet needs of children born with heart conditions and their caregivers and help families of children with heart conditions plan for the future.

If we have contacted you in error and your child was not born with a heart condition, please contact the CHSTRONG-KIDS Project Manager at [email] or [phone number] so that we can update our records.

Thank you in advance for completing this important survey.

[Site PI written and electronic signature]