Letter sent with survey

Dear Parent or Guardian of «firstname»,

«city», «state» «zip»

We invite you to take part in the Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG of KIDS (CHSTRONG-KIDS), a survey to examine the unmet needs of children born with heart conditions and their parents or caregivers. 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). Your child «childsfirstname» 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 a 20-minute survey about your child and their health, quality of life, and access to care. Your information will help us identify unmet needs of children born with a heart condition. To learn more about this project, you can visit <webstee address>.

None of your answers will be linked to your name or your child's name. Your child's name will never be released as having a heart condition. Your name will never be released as having completed the survey or having been asked to participate. We know your time is valuable. As a thank you, we have included a \$5 gift card for you to keep whether or not you complete the survey. If you complete the survey, we will send you another \$20 gift card.

You can complete the enclosed paper survey and return it to us by mail in the enclosed envelope. If you prefer to complete the survey by telephone, please call [phone number] and leave a message for us to call you back. To complete the survey online, scan the QR code in the upper right corner of this letter by opening your Camera app or QR Code Reader app on your smartphone and pointing your camera at the QR code. If a hyperlink appears, click it to go to your survey. Otherwise, your phone might automatically take you to your 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. Additionally, this information may help families of children with heart conditions plan for the future.

If you have questions about CHSTRONG-KIDS or 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 for completing this important survey.

Sincerely,

[Site PI written and electronic signature]

Si desea llenar la encuesta en Español, favor de enviar un correo electrónico a [email] o llamar al [phone number]. Haddii aad rabto in aad sahanka ku qaadato Af-Soomaali, fadlan u soo dir email [site email] ama wac [site phone number].

Enclosures: Survey Gift card Participant Information Sheet (this explains your rights as a survey participant)	Affix gift card here.