



Department of Health

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Governor

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Acting Commissioner

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Executive Deputy
Commissioner

January 22, 2021

Dear parent/guardian of <<adolescent first name>> <<adolescent last name>>,

The New York State Department of Health is inviting you to participate in a survey about the experiences of parents of children with congenital heart defects. You were contacted for this survey because you have been identified as the parent or guardian of a child with a congenital heart defect.

In this survey, you will be asked about your perceptions of your adolescent's quality of life, healthcare access, and readiness to transition from pediatric to adult care. The survey will take between 10 and 15 minutes to complete. Survey responses will be used to develop educational materials for families of children with congenital heart defects. This survey is being sponsored by the Centers for Disease Control and Prevention through a grant entitled "Surveillance of Congenital Heart Defects across the Lifespan."

Participation in this survey is entirely voluntary. You will not be penalized in any way if you decide you do not want to participate. If you choose to complete and return the survey, we will mail you a \$10 pre-paid gift card.

You will receive a reminder postcard about this survey in about a week, followed by a reminder letter and a second copy of the survey in about a month if we have not heard from you. If you have any questions about this survey, please contact Kristin Sommerhalter, the Congenital Heart Defects Survey Coordinator, by phone at (518) 402-7985 or by e-mail at kristin.sommerhalter@health.ny.gov.

If you agree to participate in this survey, we would ask that you:

- 1.) Read and sign the enclosed consent form**
- 2.) Complete the enclosed questionnaire**
- 3.) Mail back your signed consent form and completed questionnaire using the pre-paid, pre-addressed envelope that we have provided**

We thank you for your consideration.

Sincerely,

Alissa R. Van Zutphen, Ph.D.
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