

ANDREW M. CUOMO Governor HOWARD A. ZUCKER, M.D., J.D. Acting Commissioner SALLY DRESLIN, M.S., R.N. Executive Deputy Commissioner

January 22, 2021

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

The New York State Department of Health would like to invite you to participate in a survey about the experiences of adolescents who were born with congenital heart defects. You are being asked to complete this survey because you have been identified as the parent or guardian of an adolescent who was born with a congenital heart defect.

The survey will ask 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.

We intend to use survey responses to develop educational material for families of individuals with congenital heart defects and for medical providers who treat individuals with congenital heart defects. This project is being funded by the Centers for Disease Control and Prevention through a grant entitled "Surveillance of Congenital Heart Defects Across the Lifespan."

**In about a week, you will receive a mailing that contains the survey as well as a pre-paid, pre-addressed envelope for sending the completed questionnaire back to us.** If you choose to complete the survey and mail it back to us, we will send you a \$10 gift card as thanks for participating.

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 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.

We thank you for your consideration.

Sincerely,

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Alissa R. Van Zutphen, Ph.D. Principal Investigator & Assistant Bureau Director Bureau of Environmental and Occupational Epidemiology

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