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To the Gaucher disease community:

In collaboration with an US Working Group on Gaucher disease and COVID-19, the NIH Gaucher Team invites patients and caregivers of individuals with Gaucher disease to participate in a survey about the experience of individuals with Gaucher disease during the 2020/2021 COVID19 pandemic. The link is below:

Survey link: <https://redcapsurvey.niddk.nih.gov/surveys/?s=79FMC88KCF>

This survey was previously circulated, and we encourage all patients or family members to either take the survey for the first time, or repeat the survey if already taken once. We are almost a year into the current pandemic, and it is important to understand both the current needs of the Gaucher community, and how those needs have changed over the last months.

You are eligible to participate in this survey if you are older than 18 years of age and are a patient with Gaucher disease or a caregiver of an individual with Gaucher disease.

Responding to this survey takes approximately 20 minutes and is entirely voluntary. The survey is anonymous. Responses to the survey (or lack thereof) will have no bearing on your relationship with the NIH or any of the participating providers. The aggregate survey data will be presented at meetings and published.

Thank you very much for your participation,

Kind Regards,

Ellen Sidransky, MD
Grisel Lopez, MD
Emory Ryan, MSN, CPNP

Members of the US Working Group on Gaucher Disease and COVID-19:
Manisha Balwani, MD, Deborah Barbouth, MD, T. Andrew Burrow, MD, Edward I. Ginns, MD, PhD, Ozlem Goker-Alpan, MD, Gregory A. Grabowski, MD, Reena V. Kartha, PhD, Priya S. Kishnani, MD, Heather Lau, MD, Chung U. Lee, MD, Grisel Lopez, MD, Gustavo Maegawa, MD, PhD, Pramod Mistry, MD, Seymour Packman, MD, Wendy Packman, JD, PhD, Carlos Prada, MD, Barry Rosenbloom, MD, Tamanna Roshan Lal, MD, Emory Ryan, MSN, CPNP, Rapheal Schiffmann, MD, Ellen Sidransky, MD and Neal Weinreb, MD.