



Ellen Sidransky, M.D.
Chief, Medical Genetics Branch
National Human Genome Research Institute
National Institutes of Health
April 20, 2020

35A Convent Dr., MSC3717
Building 35A, Room 1E623
Bethesda, Maryland 20892-3717
Phone: (301) 496-0373 office
Fax: (301) 402-6438
Email: sidranse@mail.nih.gov

To the Gaucher disease community:

In collaboration with the US Working Group on Gaucher disease and COVID-19 (members listed below), 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 COVID19 pandemic. The link is below:

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

We hope to address whether some individuals with Gaucher disease might be more vulnerable to infections. We are also aware that some patients with Gaucher disease are facing challenges in getting their treatments and medical care since the pandemic began. We are inviting you to complete a survey to help us better understand the impact of the COVID19 pandemic on the Gaucher disease community. Since this is a continuously evolving situation, we may ask you to complete the same survey every 4-8 weeks. The results will help to inform providers on how to better serve the community during the pandemic and also help with future preparedness. It will also teach us more about the rate of COVID-19 infection among patients with Gaucher disease and the disease severity.

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.