COVID in Communities

Spring 2021 Newsletter

This collaboration is led by **NIH scientists**: Dr. Beth Kozel (NHLBI), Dr. Robert Hufnagel (NEI), and Dr. Tiffany Powell-Wiley (NHLBI) in collaboration with many NIH physicians/researchers and community groups.

Thank you for being a part of our COVID in Communities survey!

Our team greatly appreciates your time and willingness to fill out the survey. Your responses to the survey will help us better understand how COVID-19 affects different health communities.

Our first survey was open for two months, starting in October 2020. We were able to collect responses from over 1,500 people representing the following rare and common conditions:

Aplastic anemia, Arterial Tortuosity Syndrome (ATS), Bronchiectasis, non-CF, CADASIL, Rare genetic eye conditions, Familial cancer syndromes (DICER1, Melanoma, Li-Fraumeni), Fragile X, g6PD deficiency, Hermansky-Pudlak Syndrome, Inherited bone marrow failure syndromes, rare immune deficiency syndromes, Loeys-Dietz syndrome, Marfan syndrome, Neurofibromatosis, Non-syndromic aortopathy, Psoriasis, Sex chromosome number variation, Sickle cell disease, vascular Ehlers-Danlos syndrome, Williams syndrome, 22q11.2 deletion/duplication syndromes, and those without a rare disease

Our early findings:

- COVID-19 frequency did not appear to be higher in any of the communities surveyed (average frequency 3.7%)
- Less than ten participants (0.4% of people surveyed) needed hospital or intensive care for COVID-19
- No disease community reported more than one member needing hospitalization for COVID-19
- No COVID-19 related deaths were reported in any of the disease communities surveyed
- ***A follow-up survey is planned in the coming months to build on these initial findings***

Extra thank you to the members of the **Williams syndrome, Neurofibromatosis, and Rare Genetic Eye conditions' communities for returning the highest number of surveys**. We appreciate your help with this important research!

For questions or comments, email COVIDinCommunities@nhlbi.nih.gov

Image credit: NIAID-RML