

February 17, 2021

Dear Government Official:

As the leading 501(c) 3 patient advocacy group in the United States for patients impacted by a peroxisomal disorder, a rare terminal genetic disease, I want to thank your state health department for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively.

As you know, President Biden announced a strategy in late January committed to vaccine distribution for high-risk individuals, specifically those with intellectual and developmental disorders, and those with underlying conditions, including rare diseases. Respectfully, I implore you to include caregivers of individuals with peroxisomal disorders in addition to all high-risk individuals as priorities in the administration of any FDA-approved or authorized COVID-19 vaccine.

Peroxisomal disorders have extensive comorbidities that can be present at birth or develop later in life. Additionally, these complex issues are progressive and often fatal in childhood. They can cause physical, developmental, and cognitive disabilities. Some hallmark symptoms of peroxisomal disorders include hearing and vision loss, hypotonia, neurological issues, seizures, developmental delay, feeding issues, adrenal insufficiency, liver and kidney issues, and disuse osteoporosis.

Peroxisomal disorders are some of the 7000 known rare diseases.¹ Patients with peroxisomal disorders (>16 years of age), and their caregivers should be included in Phase I (high-risk populations) of the COVID-19 vaccination administration. Due to the complexity of the disorder, patients with a peroxisomal disorder are at increased risk for poor outcomes due to infection with the novel coronavirus. The effects of COVID-19 would be devastating for an individual with a peroxisomal disorder, regardless of age, who is often already at a high risk for neurological and organ damage during times of increased stress on the body.

To minimize the risk of exposure and transmission, I strongly urge you to include individuals with a peroxisomal disorder (>16 years of age) and their family members and caregivers in Phase I (high-risk populations) COVID-19 vaccination administration. These caregivers are essential to the overall health, safety, and security of patients with this rare genetic disease. Just as important – if caregivers contract COVID-19, isolation from their loved one could cause severe, irreversible damage to the patient with a peroxisomal disorder.²

On behalf of all families impacted by a peroxisomal disorder in the United States, I welcome the opportunity to discuss this request further. Should you need additional information, please contact me via email: Melissa@thegfpd.org or (918) 230-7713.

Respectfully submitted,



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¹ "FAQs About Rare Diseases." *National Center for Advancing Translational Sciences (NCATS)*. Updated 11/30/2017. Accessed via web: <https://rarediseases.info.nih.gov/diseases/pages/31/faqs-about-rare-diseases#:~:text=How%20many%20rare%20diseases%20are,at%20between%2025-30%20million.>

² Wong, Allen, Carl, Tyler, and Emily Johnson. "Joint Position Statement on Equity for People with Intellectual and Developmental Disabilities Regarding COVID-19 Vaccine Allocation and Safety." *American Academy of Developmental Medicine & Dentistry*. Updated 12/9/2020. Accessed via web: <https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5fd9690f9e3b1725e3d0d3e2/1608083731221/Covid19Vaccine-IDD-Statement.pdf>.

