The Honorable [Insert Governors Name]
Governor of [Insert State]

[Insert Mailing Address]

February X, 2021

Dear Governor [XXXX]:

As a parent/guardian/caregiver of a loved one with tuberous sclerosis complex (TSC), a rare genetic disease, I want to thank your state health department for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. Respectfully, I encourage you to include individuals with TSC in addition to the primary guardians of high-risk individuals as priorities in the administration of any FDA-approved or authorized COVID-19 vaccine.

TSC has extensive comorbidities that can be present at birth or develop later in life. Additionally, these complex issues are progressive and can cause physical, developmental, and cognitive disabilities.Manifestations can include cardiopulmonary dysfunction, disease, and abnormalities; neurological deficits such as seizures; chronic kidney disease; immunosuppression; poor growth; loss of muscle coordination; muscle weakness and pain; vision and/or hearing loss; gastrointestinal issues; intellectual and learning disabilities; autism spectrum disorder; and organ failure.[[1]](#endnote-1) Approximately 50,000 people in the United States have TSC.

I strongly believe those with TSC (>16 years of age) and family members or guardians of those at high risk should be included in Phase I (high-risk populations) of the COVID-19 vaccination administration. Due to the complexity of this disorder, our loved ones are at increased risk for poor outcomes due to infection with the novel coronavirus. The effects of COVID-19 could be devastating for my loved one or family member with TSC, regardless of age, who is often already at a high risk for neurological and organ damage during times of extra stress on the body. The pandemic has already curtailed access to numerous and desperately needed vital resources as well as delayed routine management due to the risk of exposure.

To minimize the risk of exposure and thus transmission, I urge you to include individuals and family members who live with and/or provide care for our loved one with TSC in Phase I (high-risk populations) COVID-19 vaccination administration. These caregivers and in-dwelling family members are essential to the overall health, safety, and security of loved ones with this rare genetic disease. Just as important – if we, the essential guardians, family members, and/or caregivers contract COVID-19, isolation from our loved one could cause severe, irreversible damage.[[2]](#endnote-2)

I welcome the opportunity to discuss this request further.

For any additional questions, you may also contact Ashley Pounders, MSN, FNP-C, Director of Medical Affairs at the Tuberous Sclerosis Alliance, apounders@tsalliance.org or (301) 562-9890.

Respectfully submitted,

[NAME]

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>. [↑](#endnote-ref-1)
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. [↑](#endnote-ref-2)