



December 21, 2020

Chair Governor Cuomo
Governor of New York State NYS State
Capitol Building Albany, NY 12224

Vice Chair Governor Hutchinson
State Capitol Room 250
500 Woodlane Ave.
Little Rock, AR 72201

Re: Ensuring protections for the immunocompromised during the pandemic

Dear Chair Governor Cuomo and Vice Chair Governor Hutchinson,

We write to you as the *Protecting the Immunocompromised Collaborative* led by the [Immune Deficiency Foundation \(IDF\)](#), [The AIDS Institute](#), the [American Autoimmune Related Diseases Association \(AARDA\)](#), the [Lupus Foundation Of America](#), and [Susan G. Komen](#). The Collaborative was formed soon after the COVID-19 pandemic began to have a united voice to ensure the needs of the immunocompromised community are considered and met, especially during these unprecedented times where our community is one of the most vulnerable.

The population of the immunocompromised is large and diverse, including people across all age, gender, race, ethnicity and socioeconomic status, accounting for about 2.7 percent of the entire U.S. population per the most recent estimates, and is believed to be growing.¹ The Collaborative has worked to establish overarching public policy tenets, grounded in medical and scientific evidence. We, the Collaborative, believe given the unprecedented times of the pandemic and the ongoing public health emergency, the following require the most urgent engagement and attention by state governments:

Re-Opening COVID-19 Guidelines

¹ Harpaz R, Dahl RM, Dooling KL. Prevalence of Immunosuppression Among US Adults, 2013. *JAMA*. 2016;316(23):2547–2548.
doi:10.1001/jama.2016.16477

- Consider policies and procedures to protect vulnerable populations as part of reopening guidelines.** While we understand states use their own metrics and thresholds to support local decision making on the opening and closing of establishments, we hope states still recognize and address the unique needs of those who are immunocompromised in those deliberations. While [NGA's policy memo outlines common measures states use to determine school opening and closing policies](#), such as: new case rates, positivity rates, hospitalizations, and emergency department visits, it does not recommend that states take into consideration underlying health conditions an individual may have that may make them more vulnerable to the virus. We urge NGA to update your memo to encourage states to put in place flexibilities that allow children and adults who are immunocompromised to be able to continue learning and working remotely.
- Policy protections to ensure there are no discriminatory or unfair consequences to individuals who are immunocompromised in implementation of recommendations.** We must also ensure that the immunocompromised are not discriminated against by reopening guidelines. For example, because of their autoimmune condition, individuals with lupus often experience a recurrent fever. This does not necessarily indicate that they have COVID-19 or are unable to work or attend school. Alternatively, some people with primary immunodeficiency (PI) do not present with a fever, even when very sick, and likely would not have one even if they had COVID-19. Policies that limit or permit entry into a workplace based off temperature checks have already been put in place, as seen in [NGA's Guidance on Reopening Businesses](#), with many trade associations and employers indicating temperature checks upon entry as a parameter to determine an employee's ability to enter or take leave. There must be a better understanding of the nuances of the immunocompromised population in such virus spreading risk-mitigation strategies businesses use. We urge you to update your [guidance](#) to reflect these needs and to prevent discriminatory actions against people based on a single factor.

Vaccination Distribution & Prioritization Plans: We understand states have to make tough decisions in considering a process to prioritize the distribution of limited vaccine resources for COVID-19 and that the phased rollout is based off [CDC's high priority populations](#). However, we would especially appreciate your recognition of the vulnerability COVID-19 poses to *all* immunocompromised populations by expanding the defined population beyond those who have received a solid organ transplant. This includes the millions of Americans living with primary immunodeficiencies (PI), those living with the human immunodeficiency virus (HIV), those living with Lupus and the many varieties of autoimmune diseases, and those living with immunodeficiencies as a result of treatment from another diagnosis, such as cancer. We also urge you to consider the following points pertaining to vaccination policy:

- The importance of adequate public vaccination uptake to attain herd immunity and appreciating vaccine hesitancy within the immunocompromised community.** Herd immunity, also known as community immunity, requires that at least 60 - 70 percent of the population is vaccinated in order to thwart the spread of a virus. Additionally,

vaccine hesitancy, the delayed acceptance of a vaccine despite availability, is commonly seen in the immunocompromised community because of fears that their bodies will respond adversely, even when the data and science indicate otherwise. This is particularly true in circumstances where the vaccine is lesser known or established, which is the case with any of the COVID-19 vaccines being brought to market. Since early adoption of novel vaccines in the immunocompromised community is low, this only elevates the importance of public trust and vaccination to attain herd immunity. NGA should support intensive state outreach campaigns to help assuage fears that many people have about vaccination. Such outreach and education campaigns must not only meet immunocompromised peoples' needs but should also focus on communities that have been historically marginalized and may need additional assistance to overcome mistrust of the healthcare system and barriers to access.

- **Not a one size fits all approach: Recognizing vaccine efficacy:** Since vaccines work by stimulating the body to produce specific antibodies, they are not effective for some people with PI, due to those individuals' inability to produce the antibodies necessary for this reaction. Relatedly, some vaccines, notably attenuated products, can be outright harmful. We encourage states to recognize the limitations in vaccination efficacy for subsets of the immunocompromised and to support other approaches to protect the community, particularly by encouraging confidence in the vaccines that are approved.
- **Subgroups within frontline workforce:** The rollout of vaccine distribution and access must develop a method that incorporates the reality that there are overlapping priority groups. For example, there are individuals who are front line healthcare workers who are also living with chronic illness that may make them more vulnerable to the most severe effects of COVID-19. We urge you to identify these sub-groups within each broad priority category and ensure that dissemination plans address these needs.
- **Consider health information privacy:** States must protect patient information and privacy when determining rollout for vaccine distribution. For those who cannot receive the vaccine due to their PI or due to ongoing treatment, privacy concerns could impact patient decision. Where vaccination could be required by employers, individuals who are immunocompromised may fear negative consequences if information on their health is disclosed to their employer or another party. As such, we ask that states carefully consider patient privacy as they develop policies and procedures for vaccine roll-out.

We appreciate the opportunity to share our group's priorities and hope you see the Collaborative as a resource moving forward when creating state policies, particularly around populations that need protections the most. If you have any questions or if you would like to discuss this further, please feel free to contact Lynn Albizo at lbizo@primaryimmune.org.

Sincerely,

Protecting the Immunocompromised Collaborative Steering Committee

Immune Deficiency Foundation (IDF)

The AIDS Institute

American Autoimmune Related Diseases Association (AARDA)

Lupus Foundation of America

Susan G. Komen Foundation