

July 10, 2020

The Honorable Mitch McConnell
U.S. Senate
317 Russell Senate Office Building
Washington, DC 20510

The Honorable Nancy Pelosi
U.S. House of Representatives
1236 Longworth House Office Building
Washington, DC 20515

The Honorable Charles Schumer
U.S. Senate
322 Hart Senate Office Building
Washington, DC 20510

The Honorable Kevin McCarthy
U.S. House of Representatives
2468 Rayburn House Office Building
Washington, DC 20515

Dear Majority Leader McConnell, Minority Leader Schumer, Speaker Pelosi, and Minority Leader McCarthy:

Re: Policies to protect and accommodate the immunocompromised during the pandemic

Dear Majority Leader McConnell, Speaker Pelosi, Minority Leader Schumer, and Minority Leader McCarthy,

As Congress continues deliberating additional legislation to respond to the novel Coronavirus (COVID-19) pandemic, including actions to resume to some level of pre-pandemic activity including opening of businesses and returning to school and work, we write to urge Congress to ensure the needs of immunocompromised Americans are adequately addressed.

The population of the immunocompromised is large and diverse, including people across all ages, sexes, races, ethnicities and socioeconomic status, accounting for about 2.7 percent of the entire U.S. population per the most recent estimates.¹ It includes people with genetic conditions like *primary* immunodeficiencies (PI) – a collection of over 400 rare disorders in which a person’s immune system fails to function properly because of genetic or intrinsic defects. It also includes people with *secondary* immunodeficiencies where external factors lead or contribute to a diminished immune system. These include individuals who test positive for the human immunodeficiency virus (HIV) which causes acquired immune deficiency syndrome (AIDS) and those with cancer and other conditions that require therapies such as chemotherapy, and bone marrow and organ transplants resulting in suppression of the immune system. Also included are individuals with autoimmune conditions in which the body’s immune system does not work properly and attacks and destroys healthy body tissue by mistake. Examples of autoimmune conditions include lupus, rheumatoid arthritis, psoriasis and Crohn’s disease. These conditions, as well as the treatment for such conditions, can result in suppressed and malfunctioning immune systems.

Along with newborns, the elderly, the immunocompromised and others with chronic conditions constitute the core of the nation’s medically vulnerable population. However, recognition of the

¹[Harpaz, Rafael. 2013 National Health Interview Survey, Centers for Disease Control and Prevention, division of viral diseases.](#)

needs of the immunocompromised, including appropriate safeguards and protections, has been inconsistent and often less-defined than other medically vulnerable populations. This gap leads to greater vulnerability during emergencies like what we are now navigating.

For the immunocompromised, even a relatively mild virus can be a grave threat. While members of this community have taken extra precautions to ensure their safety, steps to resume pre-pandemic activity are highly risky to those who are immunocompromised. This is particularly challenging if recommended safety guidelines are unclear, varying or not fully adhered to by the public.

To ensure the necessary safeguards are in place to protect the immunocompromised and other vulnerable populations, we urge Congress to ensure the federal government engages on this issue. To date, we have not seen a coherent approach to developing, recommending and implementing policies that focus specifically on the needs of the immunocompromised in the context of a reopening or resumption of pre-pandemic activities. This is a major gap that will lead to, at best, a patchwork of policies, and at worst, no guidance at all, that speaks to the needs of the immunocompromised.

Specifically, we ask Congress to **task the Centers for Disease Control and Prevention (CDC), to work with the immunocompromised stakeholder community and related health experts to develop and regularly update recommendations aimed at addressing the needs of the immunocompromised for the current and any future pandemics.** These recommendations should include recognizing the needs of this population and ensuring immunocompromised individuals are provided protections and accommodations to meet these needs. In addition, these recommendations and resulting state and federal policies should include flexibility to ensure that individuals are treated fairly without discriminatory consequences.

We would encourage this undertaking to be thorough and include the following:

1. Policies and procedures to protect vulnerable populations as part of reopening guidelines.

Example:

As states and municipalities move to resume some level of pre-pandemic activity, policies such as mask wearing, social distancing and capacity limitations should recognize and address the unique needs of those who are immunocompromised. As offices and schools begin opening, there must be flexibility to ensure that children and adults who are immunocompromised are still able to work remotely if that is needed.

2. Accessing healthcare services, including necessary services when closure orders are in effect.

Example:

Those who rely upon infusion therapies or oral chemotherapy and the related healthcare services that can be provided in the home should have access without barriers to minimize the need for immunocompromised individuals to leave the safety of their home when closure orders are in effect. While some changes have been implemented under Medicare and by private insurers, there are still access barriers impeding timely access to home-based care. Individuals who are immunocompromised should not have to

choose between accessing necessary care and exposing themselves to the virus when patients and their treating providers agree their treatments can be safely provided in the home.

2. Continued access to home healthcare services as states reopen and after the current pandemic ends.

Example:

Immunocompromised individuals have benefited from being able to access care telehealth during the pandemic without coverage barriers. Concerns about being exposed to viruses and other pathogens will likely continue even after the Public Health Emergency (PHE) ends. Ongoing access to care telehealth, as well as other home health services, including infusion services discussed above are needed to protect the immunocompromised for the foreseeable future.

3. Policy protections to ensure there are no discriminatory or unfair consequences to individuals who are immunocompromised in implementation of recommendations.

Example:

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 or are not able to work or attend school. Policies that limit individuals simply due to the presence of a fever would have a discriminatory impact on such individuals. 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. These individuals may be expected to participate in work or school even though they should not. There must be flexibility in policies to accommodate the specific needs of immunocompromised individuals.

4. The importance of adequate vaccination uptake, once developed, to protect the public, particularly vulnerable populations like the immunocompromised.

Example:

Some immunocompromised individuals such as those with PI have impaired immune systems and do not produce adequate antibodies to fight infections. Since vaccines work by stimulating the body to produce specific antibodies, they are not effective for some people with PI. And some vaccines, notably attenuated products, can be outright harmful. As a result, immunocompromised populations rely upon herd immunity for protection. 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. Even before the pandemic, immunocompromised communities were concerned about the growing anti-vax movement which has put our communities at risk for all kinds of communicable diseases for which there is a vaccine.

5. Other items, as warranted, particularly emerging challenges.

As a group united by the compromised immune systems of our constituencies, we stand ready to work with you to advise on and ensure that federal policies recognize the needs of the immunocompromised. We thank you for considering this request. If you have any questions or if you would like to discuss this further, please feel free to contact Lynn Albizo at lalbizo@primaryimmune.org.

Sincerely,

Immune Deficiency Foundation (IDF)
American Autoimmune Related Diseases Association (AARDA)
Lupus Foundation of America
Advocacy & Awareness for Immune Disorders Association (AAIDA)
The AIDS Institute
ALPHA-1 FOUNDATION
The American Liver Foundation
APS Foundation of America, Inc
Arthritis Foundation
Autoimmune Encephalitis Alliance, Inc
CancerCare
Chronic Care Collaborative
Chronic Care Policy Alliance
Chronic Disease Coalition
Colorado Gerontological Society
DPHSS FHRC
Family Voices
Family Voices NJ
GBS|CIDP Foundation International
Global Healthy Living Foundation
International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)
International Pemphigus Pemphigoid Foundation
Lupus and Allied Diseases Association, Inc.
Multiple Sclerosis Association of America (MSAA)
The Myositis Association
National Eczema Association
National Health Council
National Hemophilia Foundation
National Kidney Foundation
National Multiple Sclerosis Society
National Psoriasis Foundation
Parent Project Muscular Dystrophy
Parents Reaching Out to Help
Platelet Disorder Support Association
Pulmonary Hypertension Association
SCID Angels for Life Foundation
Sjogren's Foundation
Solve ME/CFS Initiative
SPAN Parent Advocacy Network (SPAN)
Susan G. Komen