August 21, 2020

Dr. Robert Redfield, M.D.
Director
Centers for Disease Control and Prevention
1600 Clifton Road, NE
Atlanta, Georgia 30329–4018

Re: Need for guidance to safeguard the immunocompromised community

Dear Dr. Redfield:

On behalf of a collaborative of organizations that represent and advocate for the interests of Americans who are immunocompromised, we write to request that the Centers for Disease Control and Prevention (CDC) work with our groups and other experts to develop and update recommendations for protecting the immunocompromised population during the COVID–19 pandemic and future public health emergencies.

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. It includes people with primary immunodeficiencies (PI) – a collection of more than 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 other factors lead or contribute to a diminished immune system. This encompasses people living with human immunodeficiency virus (HIV), as well as those with cancer, recipients of bone marrow and organ transplants, and those with other conditions being treated with medications that suppress the immune system. Also included are individuals with autoimmune conditions such as lupus, rheumatoid arthritis, psoriasis, type 1 diabetes, and Sjogren’s syndrome. These and other autoimmune conditions, as well as the treatment for such conditions, can result in suppressed and malfunctioning immune systems.

We appreciate the CDC including the immunocompromised on its website section focused on the coronavirus and for including a set of recommended actions. However, with the expertise of those living with immunocompromised conditions, we at the Protecting the Immunocompromised Collaborative can provide comments and additional recommendations to improve upon this section. We would like to see the agency provide a more complete set of guidelines to help address the host of issues and challenges that our population must navigate.

A number of our organizations have been fortunate to have longstanding and productive partnerships with CDC to address the needs of our community. We believe these existing relationships and programs make the CDC uniquely positioned to address this request. These

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needs are particularly necessary at this time as the nation navigates the challenges associated with reopening and resumption of pre-pandemic activities.

As the CDC navigates several priority issues with regard to the pandemic, it is essential to include the development and issuance of formal guidance on measures to safeguard the immunocompromised community. To ensure that these policies are responsive to those impacted, we request that the CDC commit to working with immunocompromised stakeholders and other experts to develop comprehensive and regularly updated guidelines to protect the health of our community. You will find, in our collaborative organizations, the expertise and willingness to work with CDC to develop this content.

As such, we request an opportunity to discuss these needs with you or other appropriate members of your team. To set up a call with representatives from the Protecting the Immunocompromised Collaborative, please email Lynn Albizo from the Immune Deficiency Foundation at jalbizo@primaryimmune.org.

We look forward to hearing from you.

Sincerely,

Protecting the Immunocompromised Collaborative Steering Committee
Immune Deficiency Foundation (IDF)
American Autoimmune Related Diseases Association (AARDA)
Lupus Foundation of America
The AIDS Institute