

The Immunocompromised Collaborative

February 22, 2022

The Honorable Patty Murray
Chair
Committee on Health, Education, Labor & Pensions
428 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Richard Burr
Ranking Member
Committee on Health, Education, Labor & Pensions
428 Dirksen Senate Office Building
Washington, DC 20510

Re: **PREVENT Pandemics Act – Protections for the immunocompromised**

Dear Chairman Murray and Ranking Member Burr:

On behalf of the Immunocompromised Collaborative, which consists of patient organizations representing the approximately 7 million Americans who are immunocompromised, we thank you for developing the PREVENT Pandemics Act in a bipartisan manner. This legislation is necessary to ensure that our nation is well prepared for further evolutions of COVID-19 and for future pandemics.

The population of the immunocompromised account for at least 2.7% of U.S. citizens across all age, gender, race and ethnicities. It includes individuals with one of the over 450 types of primary immunodeficiencies (PI) in which a person's immune system fails to function properly because of genetic or intrinsic defects and those with secondary immunodeficiencies where other factors lead or contribute to a diminished immune system. These include people living with human immunodeficiency virus (HIV), those with cancer, recipients of bone marrow and organ transplants, and individuals 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.

Overall View

We hope that this legislation will be enacted into law this year particularly given the many unknowns of COVID-19, the long-term risks, and the high likelihood of future pathogenic threats. As you move this legislation through the markup process, we encourage you to incorporate policies that speak to the needs of the immunocompromised including within policies that pertain to (1) special populations and needs, and (2) prioritization of preventative and therapeutic measures. With this view in mind, the following are specific recommendations connected to provisions within the discussion draft:

- **Sec. 104. Strengthening Public Health Communication:** We support the intent of this section and encourage that the following language be added under duties:
 - “Strategies to identify specific populations in need of targeted evidence-based information, to reach these populations, and to clearly communicate targeted messages to these populations.”

We believe this amendment or similar language will capture the need for tailored evidence-based messages to specific populations such as the immunocompromised.



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- **Access to Care During Public Health Emergencies:** We support Sec. 112 which focuses on ensuring provision of mental health services during public health emergencies. Additionally, we encourage the Committee to consider crafting a corresponding provision that pertains to access to healthcare more broadly, including in alternate sites of care, notably the home. For those who are immunocompromised, being in public locations during the peak of the COVID pandemic or any subsequent pandemic is even more life-threatening than for the general population. During the public health emergency (PHE), the Centers for Medicare & Medicaid Services (CMS) took action to make home-based care more widely accessible to Medicare beneficiaries who ordinarily would not qualify for such care. This example makes clear a need to focus on full access to all types of healthcare during future PHEs, not limited to mental health. We encourage recognition of this and tasking of a more expansive plan, under the auspices of the Office of the Secretary, to address these concerns.

Securing Continuity of Care—Similar to our suggestion above, we encourage the Committee to consider a more broad interpretation of Sec. 112 or create a separate provision regarding continuity of care during a PHE. Throughout the pandemic, many patients experienced disruptions to routine care necessary for management of chronic and acute conditions. Due to the strain on healthcare capacity during the pandemic, many people delayed life-saving services related to screening, disease surveillance, surgical care, treatment, and more. For example, many patients were forced to delay “elective” surgeries to remove cancer and others still had to delay potentially life-saving treatments due to capacity concerns. This is especially harmful to those patients who may have required additional delays due to their immunocompromised status. We ask the Committee to examine these delays in everyday care because of the pandemic and devise a way to mitigate the impact this could have on patients.

- **Sec. 211: Modernizing Biosurveillance Capabilities:** We strongly agree with the clear need to enhance capturing and reporting data on emerging infectious diseases. The shortcoming of our nation’s current capabilities throughout the pandemic has been clear and the need for modernization is essential. We appreciate that the draft speaks to data pertaining to at-risk populations (page 71) and urge that you continue to include this reference. Further, we recommend that you consider strengthening the focus on such populations to ensure data collected informs ongoing public health policies and recommendations, including prioritization for treatments and means of prevention.
- **Sec. 232. Vaccine Distribution Plans:** The Immunocompromised Collaborative has been deeply engaged on the issue of access to vaccines, including prioritization for at-risk populations. We support expanding this provision beyond flu and urge the committee to consider other targeted amendments to reflect the needs of at-risk populations including access and distribution of other types of prophylactic medications and antivirals aimed at immunocompromised individuals who are not fully responsive to vaccines.
- **Sec. 301. Research into the Long-term Effects of COVID:** We support this provision and would recommend that the committee include a reference to the impact on “immunocompromised and other high-risk populations” to ensure our communities are not overlooked and to recognize the heightened risk faced by this community.



- **Sec. 502: Modernizing Clinical Trials.** We applaud the Committee for considering strategies to mitigate disruptions in clinical research during the PHE. Many patients facing conditions with limited treatment options rely on clinical trials for innovative approaches to care. Additionally, we believe efforts to modernize clinical trials could positively impact the inclusion of underrepresented populations in research and improve health equity. We strongly support requiring the FDA to provide guidance to researchers on utilizing digital health technology, decentralizing clinical trials, and innovating in clinical trial design to both prevent disruptions in patient care and improve access.

We thank you again for initiating this important legislation to help prepare us for future pandemics and appreciate the opportunity to submit comments focused on immunocompromised populations. If you have any questions or would like additional information related to immunocompromised populations, please contact Lynn Albizo at lalbizo@primaryimmune.org.

Sincerely,

American Academy of Allergy, Asthma & Immunology (AAAAI)
Autoimmune Association
Color of Crohn's and Chronic Illness
CLL Society
Family Voices NJ
Foundation For Sarcoidosis Research (FSR)
Immune Deficiency Foundation
Lupus Foundation of America
Lupus and Allied Diseases Association, Inc.
Lymphoma Research Foundation
Platelet Disorder Support Association
SCID Angels for Life Foundation
Solve M.E.
SPAN Parent Advocacy Network
Susan G. Komen
TRAIPAG- Transplant Recipients and Immunocompromised Patient Advocacy Group

