IDSA
Infectious Diseases Society of America

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The Honorable Bernie Sanders
Chair
Senate HELP Committee
Washington, DC 20510

Dear Chairman Sanders:

Thank you for the opportunity to provide input on your Long COVID legislative proposal.

On behalf of the Infectious Diseases Society of America (IDSA) and more than 13,000 physicians, scientists, public health practitioners and other clinicians specializing in infectious diseases prevention, care, research and education, I thank the Committee for focusing on this important issue.

As you know, today at least 22 million Americans are estimated to suffer from Long COVID. This has an immense impact on their health and quality of life. IDSA offers the following recommendations to address the scope and severity of the problem of Long COVID.

Resources to Address Long COVID

IDSA appreciates the funding Congress has provided in the past to address the COVID pandemic and Long COVID. The mandatory funding of $1 billion over 10 years in the legislative proposal is a good start; however, Congress should assess resource needs over time to ensure funding provided meets the necessary research and treatment challenges. In addition, investments in Long COVID must not take the place of equally critical investments in our health care system, public health and biomedical research capacity to address other emerging or ongoing infectious diseases needs.

Legislation to address Long COVID should continue support for and expand the Agency for Healthcare Research and Quality Long COVID Care Network. It can be difficult for patients who suspect they have Long COVID to find providers who are experienced in treating it. They often see multiple specialists for various Long COVID symptoms before finding appropriate health care. Long COVID clinics should be expanded to more places to ensure greater access to care. In addition, Congress should explore additional options to support clinics and expand education about Long COVID among health care providers.

Long COVID Research Topics

Research into Long COVID should address other post-acute syndromes including myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Some patients experiencing Long COVID also experience ME/CFS, which has significant overlap and similar pathophysiology. The study of additional post-acute syndromes may offer insight into Long COVID.

- In addition to exploring off-label uses of current pharmaceutical products, research should study non-pharmaceutical interventions including physical therapy and behavioral- and nutrition-focused changes.
- Funding should also support epidemiological studies to more accurately measure the incidence and prevalence of Long COVID and trends in patients who suffer Long COVID symptoms, including data on age, race/ethnicity, gender and other demographics.
    - Additionally, funding should support research into how COVID reinfection impacts patients who suffer from Long COVID, the risk of Long COVID from reinfection and implications for frequency of vaccination.
- To ensure broad expertise is harnessed to better understand treatment of Long COVID, Congress should expand funding for Long COVID adaptive platform repurposed drug trials, independent of the RECOVER mechanism.
- The quick turnaround process described in the legislative proposal for clinical trials should also apply to mechanistic and epidemiological studies.

Long COVID Clinical Trials

To increase diversity and equity in Long COVID clinical trials, it is critical to develop, strengthen and sustain relationships with underrepresented communities through increased outreach to community-based organizations and faith-based institutions that have established trust in underrepresented communities. When working with underrepresented communities in clinical trials, communication should be transparent and focus on trial procedures, importance of trial participation and impacts and side effects when applicable. Transparency in these communications builds trust with the community and the populations researchers seek to work with. All written materials used in the study, especially consent forms, should also be available in multiple languages to encourage accessibility for participants. Additionally, ensuring translators are readily available for participants is important to increase inclusion and demonstrate a respect for participants and stronger cultural competency in clinical trial design.

Diversity in clinical trial staff is also critical. Research from Tufts found that clinical trial sites with higher racial and ethnic diversity among staff members saw higher enrollment of patients from minority groups. These sites were also more likely to report that they viewed diversity as a critical part of operating procedures and research success. This prioritization of diversity can support more favorable views of researchers and trials by the communities that researchers seek to work with and is critical in furthering diversity, equity, inclusion and access in clinical trial research.

Clinical trial design should prioritize carrying out trials and procedures at facilities in areas easily accessible to underrepresented populations experiencing Long COVID. Providing transport or ensuring trial locations are near public transit locations can alleviate transport concerns. Telehealth and use of mobile vans can help reduce barriers to participation for patients with Long COVID symptoms that make travel outside their home difficult. These methods of participation are also critical to extend clinical trial participation to rural communities and to urban health care deserts with limited or no clinical or clinical trial sites.

Additional Recommendations

IDSA appreciates the attention given in the legislative proposal to the need for collection of data and access to data for health professionals, patients, industry and the public. Public health officials should also be granted access to the biological data bank of clinical information from Long COVID patients so they can understand the epidemiology of Long COVID and risk to residents of their communities and states.

To foster provider education about Long COVID and keep pace with emerging research, IDSA recommends that the National Institutes of Health hold an annual conference for Long COVID experts and other researchers and clinicians in addition to the conference mentioned in the legislative proposal.

Thank you again for your attention to this important issue. Please direct any questions to Eli Briggs, IDSA director of public policy, at ebriggs@idsociety.org.

Sincerely,

Steven K. Schmitt, MD, FIDSA, FACP
President