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Long Covid Research Needs A Moonshot; Patients Applaud Bipartisan Senate Hearing <u>Patients From Across Nation Represent Long Covid at Senate HELP Committee Hearing</u>

On Thursday, January 18, 2024, a delegation of Long Covid Moonshot supporters traveled to Washington DC to raise awareness about Long Covid and advocate for annual, dedicated NIH research funding.

Long Covid Moonshot is a grassroots advocacy collective pushing for a dedicated \$1B+ in annual NIH research funding for 10 years to pursue treatments and cures for Long Covid. When the *Addressing Long Covid:*Advancing Research and Improving Patient Care hearing was announced on January 11, Long Covid Moonshot quickly mobilized, organizing patients on social media to urge senators on the HELP Committee to attend the hearing, producing materials and t-shirts, and using crowdfunding to raise travel funds for advocates.

This rapid action was especially challenging for people living with Long Covid, who, as Senator Tim Kaine (D-VA) recognized during the hearing, had to "come over a mountain" to be present, due to the physical and financial impacts of Long Covid on their lives. Despite these difficulties, the hearing was packed, with 14 senators in attendance and an audience sporting teal Long Covid Moonshot T-shirts spilling into the overflow room.

Chair Bernie Sanders (I-VT) opened the meeting by framing the scale of the crisis and recognizing that Long Covid "has not gotten the attention that it deserves." Senators asked thoughtful questions of the panel and showed bipartisan concern for the devastation wrought by Long Covid, with Senator Kaine sharing about his own and other lawmakers' struggles with Long Covid, Senator Bill Cassidy (R-LA) expressing his empathy for those struggling with Long Covid and similar conditions like ME/CFS, and Senator Roger Marshall (R-KS) speaking movingly of a loved one who was struggling with Long Covid.

The hearing included testimony from patients, the parent of a child with Long Covid, and clinicians/researchers. All panelists affirmed the need for more funding from Congress to address Long Covid, with Dr. Ziyad Al-Aly calling existing clinical trials "too slow and too small to help" and Dr. Charisse Madlock-Brown calling for "a moonshot initiative to tackle Long Covid."

"Today's Senate HELP Committee demonstrated strong bipartisan support to address the Long COVID crisis through funding and accelerating research," said advocacy collective Long Covid Moonshot. "We are grateful to HELP Committee Chair Sanders for his support and for convening this important hearing, and for productive meetings with the offices of the White House, Senate Majority Leader Schumer, and Senators Markey, Casey, and Smith. We are looking forward to working with Congressional Long Covid champions like Senators Marshall, Murkowski, and Cassidy. Working across the aisle, we believe that a dedicated Long Covid Moonshot research fund would take us from zero FDA-approved treatments to effective medicines and accessible care for the 16 million Americans facing Long Covid today."

Long Covid Moonshot thanks the Senate HELP Committee for holding this hearing and for their insightful questions, the panelists for their powerful testimony, and the patients and allies who have advocated for years for recognition and support for people with Long Covid.