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Hearing Summary

April 29, 2021

ENERGY AND COMMERCE HOLDS FULL COMMITTEE HEARING ON COVID-19 LONG-HAULERS

EXECUTIVE SUMMARY

Yesterday, the House Energy and Commerce Subcommittee on Health held a hearing entitled "The Long Haul: Forging a Path through the Lingering Effects of COVID-19." Committee members questioned two panels of witnesses. The first panel consisted of leaders from federal health agencies, and the second panel included physicians and patients dealing with Long COVID. Committee members were particularly interested in how the National Institutes of Health (NIH) is using a **$1.15 billion investment from the December 2020 Consolidated Appropriations Act**. Witnesses shared insights into **data collection**, **electronic health record (EHR) utilization**, **educating physicians about Long COVID**, and **emerging research**.

Democrats inquired about links between Long COVID and **myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)**, and witnesses discussed the importance of Long COVID research for the ME/CFS community. Members asked about the patient experience with Long COVID, and witnesses depicted hurdles ranging from stigmas around the condition to social determinants of health. Committee members and witnesses also touched on the state of **government coordination to support Long COVID research**.

OPENING STATEMENTS

Chairwoman Anna Eshoo (D-CA) (statement) reiterated CDC findings on Long COVID and noted millions of Americans are dealing with this disease. She stressed that long-haulers need to be taken seriously in the medical field. Chairwoman Eshoo suggested Long COVID treatment centers across the U.S. and foreshadowed the millions of dollars coming out of the NIH within the next few days in the form of grants to COVID long haul research.

Ranking Member Brett Guthrie (R-KY) supported the Ensuring Understanding of COVID-19 to Protect Public Health Act (H.R. 6701). He was anxious to hear about how the NIH is utilizing its $1.15 billion funding, and he was eager to learn more about how CDC and NIH are working to learn more about this disease.

Full Committee Chairman Frank Pallone (D-NJ) (statement) said that Long COVID can be even more difficult than initial COVID infections. He added that women, older adults, and health care workers are most susceptible to the disease.

Full Committee Ranking Member Cathy McMorris Rodgers (R-WA) said that the causes and treatments for long-term COVID symptoms are a top priority. She shared the story of a constituent battling Long COVID to the point of needing a lung transplant. Ranking Member McMorris Rodgers also touched on Long COVID research efforts in Washington.

WITNESS TESTIMONY

Panel I

Francis S. Collins, M.D., Ph.D., (testimony), Director of the NIH, noted his efforts last year to push for COVID long-haul research and expressed his gratitude for the $1.15 billion in NIH funding. He spoke directly to the patient community, assuring them that "we believe you, and we hear you." Dr. Collins wants to study tens of thousands of patients from varying backgrounds. He explained launching a meta cohort by using data from electronic health records. The NIH will use mobile health apps and wearable devices to conduct research and will be awarding grants in the coming weeks.

John T. Brooks, M.D., (testimony), Chief Medical Officer of the CDC COVID-19 Response, noted three distinguished classes of post-COVID conditions identified by the CDC: (1) Long COVID; (2) long-term damage to organs; and (3) lasting complications from COVID treatment and hospitalization. He explained that the CDC is working to accumulate better data on these patients through electronic health records and other systems. Dr. Brooks also elaborated on CDC long-term surveillance possibilities and guidance for primary care physicians on these conditions.

Panel II

Natalie Hakala (testimony), a patient, discussed her mild COVID symptoms, followed by pneumonia, extreme fatigue, and numerous other serious health concerns as a symptom of Long COVID. She was unable to make breakfast, get out of bed, shower, or watch television. Her eventual vaccination has helped her slowly improve, but she still cannot work full time.

Chimere Smith (testimony), a patient, discussed the impact of being a Black, disabled, poor woman living with COVID. She also drew attention to the racial and gender inequities in public health. Ms. Smith explained she can no longer teach, and she told the committee that she was blinded for five months because physicians ignored her complaints of glaucoma. She stressed better funding for ME/CFS to understand its intersection with Long COVID and physicians' racial bias.

Lisa McCorkell (testimony), a patient and Team Lead of Patient-Led Research Collaborative, experienced physician bias and spoke about her Collaborative's findings. She depicted the ripple effects of the impact of Long COVID, including health insurance coverage and paid leave. Waiting lists for post-COVID patients are full, and Ms. McCorkell was grateful to ME patients that suggested she pace herself while continuing to work through her symptoms.

Jennifer Possick, M.D. (testimony), Associate Professor of Critical Care and Sleep Medicine and Pulmonologist at Yale School of Medicine, described her experiences working with Long COVID patients. Mounting medical experiences is only one of the hurdles that her patients face, and she

discussed the huge influx of post-COVID patients at her clinic. She made three suggestions: (1) increase public awareness for post-COVID disease; (2) ensure early and equitable access to care including the elimination of prior authorization and coverage issues; and (3) address the seriocomic impacts on patients such as inability to work and obtain health insurance.

Steven Deeks, M.D. (testimony), Professor of Medicine at the University of California, San Francisco, discussed stigma in the medical community, the spectrum of symptoms that may require different solutions, and differentiating disabling disease due to COVID from a four to twelve week recovery period. Dr. Deeks also touched on factors that are still unknown, including the prevalence of these conditions and natural history. He added that women and marginalized communities are more likely to have post-COVID and said that the private sector should fill the need for treatments once the NIH identifies the mechanism.

DISCUSSION AND QUESTIONS

Connections to ME/CFS

- Dr. Brooks explained to Ranking Member McMorris Rodgers that while post-COVID diseases share similarities with ME/CFS, and both conditions are generally catalyzed by previous illnesses, Long COVID should be researched separately.
- On the other hand, **Rep. Kurt Schrader (D-OR)** noted that he spoke with ME/CFS constituents and wondered if Long COVID could cause ME/CFS. Dr. Collins highlighted the overlap between ME/CFS and Long COVID, and he hoped that the two conditions can be studied in conjunction to learn more about the causes of ME/CFS. He added that ME/CFS has been an enduring focal point for him.
- **Reps. Neal Dunn (R-FL)** and **Debbie Dingell (D-MI)** also spoke with groups of ME/CFS and patients, and they echoed possibilities of overlapping research. Dr. Brooks reiterated Dr. Collins' sentiments that research on Long COVID will have great benefits to the ME/CFS community.
- Ms. McCorkell told Rep. Dingell that NIH research grants should include patients with ME/CFS to compound on a study's utility.
- In response to **Rep. Robin Kelly (D-IL)**, Ms. Smith included ME/CFS patients in her push for more equitable health care.
- **Rep. Lori Trahan (D-MA)** agreed with Rep. Schrader and classified ME/CFS as a possible symptom of Long COVID. She advocated for funding more ME/CFS research with the $1.15 billion in funding for the NIH from the December 2020 funding package.
- **Rep. Lizzie Fletcher (D-TX)** expressed her appreciation for members and witnesses that emphasized the importance of ME/CFS solutions.

Emerging Research, Studies & Treatment Tools

- Dr. Collins told Chairwoman Eshoo that the meta cohort study will conclude soon, award grants within the next three weeks, then stand up Long COVID treatment and research facilities. Dr. Possick added that there are currently 60 clinics addressing Long COVID, and none of the clinics are coordinated.

- Dr. Possick suggested that primary care physicians create a care infrastructure for long-haulers. Dr. Brooks described CDC efforts to educate physicians about Long COVID, including Clinician Outreach and Communication Activity (COCA) calls and webinars with thousands of providers, and imminent guidance from the CDC.
- Witnesses stressed the importance of continuity of care and having clinics that offer patients access to a variety of specialties.
- Dr. Collins told Ranking Member Guthrie that 23 percent of long haulers felt better after receiving the vaccine, while 15 percent noticed no change. Dr. Brooks told **Rep. Gus Bilirakis (R-FL)** that early research indicates that vaccinations may help.
- Drs. Brooks, Deeks, and Possick stressed the importance of creating a definition for Long COVID in order to identify treatments. Dr. Brooks told **Rep. Peter Welch (D-VT)** that proposed definitions should include patient and physician consultation, and Dr. Collins suggested to **Rep. Kurt Schrader (R-OR)** that a clear definition needs to be paired with a viral or antibody test.
- Dr. Brooks said that EHRs and research cohorts are critical for gathering data on Long COVID, and he cited a recent Morbidity and Mortality Weekly Report (MMRW) report with Kaiser Permanente of Georgia that evaluates the use of EHRs in Long COVID research. He remarked on the plentiful recourses for research due to the "unprecedented" prevalence of Long COVID. However, he explained to **Reps. Doris Matsui (D-CA)** and **Kathleen Rice (D-NY)** that tracking mental health components of Long COVID through EHRs is difficult due to a lack of direct patient assessment.
- Dr. Brooks said that machine learning is another useful tool to gather and analyze patient data. Dr. Collins told **Rep. John Curtis (R-UT)** that machine learning can help predict Long COVID by analyzing the first seven days of acute COVID. Dr. Collins also noted that patients with high body mass index (BMI) and obesity are more likely to develop Long COVID.
- In response to **Rep. Michael Burgess (R-TX)**, Dr. Deeks suggested a program for Long COVID that mirrors the Ryan White Program.
- Dr. Brooks hinted that new research is "in the pipeline" and will be published through the MMWR and the St. Louis Missouri VA Medical Center.
- Dr. Collins told **Rep. Larry Bucshon (R-IN)** that the recent $1.15 billion investment in the NIH is being spent on research and trails to address acute COVID with anticoagulants and exploring new opportunities to conduct randomized control trials (RCTs), as well as the possible use of steroids and immunosuppressants.
- **Rep. John Joyce (R-PA)** inquired about monoclonal antibody treatments, and Dr. Collins explained that the Accelerating COVID-19 Therapeutic Interventions and Vaccines (ACTIV) program is working on therapeutic agents with pharmaceutical partners. Dr. Collins also told **Rep. Michael Doyle (D-PA)** that a new ACTIV-6 trial is testing oral agents for COVID, and ivermectin is a strong candidate for the trial.

The Patient Experience

- Ms. Smith discussed the importance of trusting Black women in the health care field. She suggested more equitable research and treatment for emerging conditions. Ms. Hakala built on the sentiment, elaborating on her experience with physicians not taking her seriously.

- Dr. Possick said that aside from implicit and cognitive biases, physicians can better address patients with Long COVID through improved CDC guidance.
- Dr. Collins told Ranking Member McMorris Rodgers that 11 to 15 percent of children with COVID become long-haulers. Dr. Possick added that the long-hauler population is getting younger. She suggested that older Americans with comorbidities may not recognize Long COVID symptoms, while a change in the quality of life for younger, otherwise healthy patients is more obvious. Dr. Collins assured **Rep. Kim Schrier (D-WA)** that the FDA is working on authorizing the Pfizer vaccine for children ages 12 through 15.
- Reps. Bucshon, **Anne Kuster (D-NH)**, **Morgan Griffith (R-VA)**, Doyle, and Carter discussed their experiences with friends and family suffering from Long COVID.
- Rep. Dunn wondered how providers will trust Long COVID patients that do not have a documented acute COVID test. Dr. Collins said that he just had a "big discussion" about T-cell testing, but there was a great deal of disagreement on how to implement that testing.
- **Reps. Tony Cárdenas (D-CA)** and **Raul Ruiz (D-CA)** voiced concerns that underserved populations are more likely to suffer from Long COVID. Dr. Collins explained that health disparities for Long COVID will mimic the racial biases in the acute COVID population. Dr. Brooks noted that the CDC has spent $3 billion on vaccine confidence in underserved communities, $2.2 billion in funding opportunities to address disparities, and $3 million to build a core of community health workers.
- Dr. Brooks assured Rep. Rice that cohorts are studying Long COVID in the Alaskan Native and Native American communities.
- Dr. Collins told Rep. Kelly that employers will not be sympathetic to employees with Long COVID without clinician support.

Government Coordination

- Drs. Collins and Brooks agreed that the NIH and CDC do not require oversight for their Long COVID research efforts. They added that working with the Food and Drug Administration (FDA) and the Center for Medicare and Medicaid Services (CMS) is working well, but they need more time before bringing ideas and research to Health Resources and Services Administration (HRSA).
- **Rep. Fred Upton (R-MI)** and Chairwoman Eshoo strongly supported the creation of the Advanced Research Projects Agency-Health (ARPA-H), modeled after the Defense Advanced Research Projects Agency (DARPA), in President Biden's fiscal year 2022 budget. They labeled the initiative as a bipartisan concern.
- Rep. Bucshon told witnesses that he will always support enhanced funding for the NIH.