9700 W. Bryn Mawr Ave., Ste. 200
Rosemont, IL 60018
www.aapmr.org

PHONE 847.737.6000
FAX 847.754.4368
info@aapmr.org

President
Deborah A. Venesy, MD, FAAPMR
President-Elect
Steven R. Flanagan, MD, FAAPMR
Vice President
D.J. Kennedy, MD, FAAPMR
Secretary
Amy J. Houtrow, MD, PhD, MPH, FAAPMR
Treasurer
Scott R. Laker, MD, FAAPMR
Past President
Stuart M. Weinstein, MD, FAAPMR
Members-at-Large
Lisa A. Merritt, MD, FAAPMR
Atul T. Patel, MD, MHSA, FAAPMR
David W. Pruitt, MD, FAAPMR
Kerrie M. Reed, MD, FAAPMR
Strategic Coordinating Committee Chairs
Inclusion & Engagement
Carla P. Watson, MD, FAAPMR
Medical Education
John C. Cianca, MD, FAAPMR
Quality, Practice, Policy & Research
Thiru M. Annaswamy, MD, MA, FAAPMR
Specialty Brand Expansion
Andre Panagos, MD, FAAPMR
Ex Officio Non-Voting Liaisons
PM&R, Editor-in-Chief
Janna L. Friedly, MD, MPH, FAAPMR
President, Physiatrist in Training Council
Heidi Chen, MD
Executive Director & CEO
Thomas E. Stautzenbach, MA, MBA, CAE

December 16, 2021

The Honorable Diana DeGette
2111 Rayburn House Office Building
Washington, DC 20515

The Honorable Fred Upton
2183 Rayburn House Office Building
Washington, DC 20515

RE: Cures 2.0 Legislation

Dear Representative DeGette and Representative Upton,

On behalf of the American Academy of Physical Medicine and Rehabilitation (AAPM&R), I write to thank you for several sections in the Cures 2.0 legislation, particularly those focused on Long COVID or Post-Acute Sequelae of COVID-19 (PASC), as they are very much in line with AAPM&R's own advocacy efforts. These legislative proposals have been a key focus of AAPM&R's own advocacy efforts and would address critical needs of Long COVID patients nationwide. I would also like to take this opportunity to encourage you to include language regarding a coordinated federal body made up of diverse experts across administrative agencies that will comprehensively address Long COVID. AAPM&R believes a coordinated response is imperative to ensure an efficient response to the Long COVID that leaves no one behind and provides health care support and more. AAPM&R would appreciate the opportunity to meet with your office to discuss this further.

AAPM&R is the national medical specialty organization representing more than 10,000 physicians who are specialists in physical medicine and rehabilitation (PM&R). PM&R physicians, also known as physiatrists, are medical experts in treating a wide variety of conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons. PM&R physicians evaluate and treat injuries, illnesses, and disabilities, and are experts in designing comprehensive, patient-centered treatment plans. Physiatrists utilize cutting edge as well as time-tested treatments to maximize function and quality of life. Due to their training and expertise, PM&R physicians are uniquely qualified to help guide the multidisciplinary planning effort needed to address the rehabilitation and care needs of this rapidly growing patient population.

Cures 2.0's Long COVID Provisions

AAPM&R released a Call to Action[1] on Long COVID early in 2021. This Call asked for a comprehensive crisis plan to address the myriad needs of patients with Long COVID. AAPM&R believes that the crisis plan must include

---

[1] AAPM&R Call to Action on Long COVID. Long-COVID-layout-March 16 (aapmr.org).

aapm&r

9700 W. Bryn Mawr Ave., Ste. 200
Rosemont, IL 60018
www.aapmr.org

PHONE 847.737.6000
FAX 847.754.4368
info@aapmr.org

resources to build necessary infrastructure, equitable access to care for all patients, and continued funding for research that advances medical understand of Long COVID. However, we also recognize that there are many needs for patients with Long COVID that go beyond clinical care, including disability evaluation and benefits, strengthened safety-net care, and others. As such, in addition to our Call to Action, AAPM&R has also advocated for a federal commission or other coordinated federal interagency group that will comprehensively address Long COVID, rather than addressing it in silos. Nearly 100 stakeholders support such a group.[2]

Since our Call to Action, AAPM&R has also convened the Multidisciplinary Quality Improvement Initiative, a collaborative of 35 Long COVID clinics which meet monthly to discuss clinical findings, best practices, and patient access to care. This group, known as the “PASC Collaborative,” writes and publishes guidance statements on treating patients with Long COVID drawn from their frontline experience with this patient population. As National Institutes of Health’s RECOVER initiative will do vital work in helping develop evidence behind the best approaches to the assessment and treatment of individuals with Long COVID, these guidance statements are designed to help clinicians treat patients with Long COVID who they are currently seeing.

Learning Collaborative: Firstly, I would like to thank you for creating the learning collaborative focused on Long COVID in section 101 and requiring regular quarterly meetings each year. Long COVID is currently estimated to affect approximately 10-30% of individuals who had COVID-19.[3,4] Given 48 million total cases of acute COVID-19[5], even with the more conservative estimate of 10%, that is nearly 5 million Long COVID cases in the United States. This number is only going to increase as variants continue to rampage the globe and continued vaccine hesitancy persists. As the incidence of Long COVID grows and we quickly learn more about this new syndrome, meeting four times annually will be imperative. The learning collaborative of individuals and organizations representing key sectors of the health care community will be vitally important in guiding the federal response to Long COVID. **I encourage you to include a recommendation for a coordinated federal body of diverse**

---

[2] AAPM&R Call to Action: America Needs a Federal Commission to Develop A Comprehensive National Plan to Defeat the Long COVID “PASC” Crisis. PASC One-Pager for Sign-Ons (D0943466).DOCX (aapmr.org)
[3] Rubin R. As Their Numbers Grow, COVID-19 “Long Haulers” Stump Experts. JAMA. 2020;324(14):1381–1383. doi:10.1001/jama.2020.17709
[4] Logue JK, et al "Sequelae in Adults at 6 Months After COVID-19 Infection" JAMA Network Open 2021; DOI: 0.1001/jamanetworkopen.2021.0830.
[5] AAPM&R Estimated PASC Cases. PASC Dashboard (aapmr.org).

aapm&r

9700 W. Bryn Mawr Ave., Ste. 200
Rosemont, IL 60018
www.aapmr.org

PHONE 847.737.6000
FAX 847.754.4368
info@aapmr.org

experts to meet with the learning collaborative to best understand how to implement a comprehensive response to the Long COVID crisis.

Long-COVID in Pediatric Populations: I would also like to thank you for including the section on Long COVID Scientific Research for Children. Part of AAPM&R's collaborative focusses on the pediatric population and we are currently working on a guidance statement for treating Long COVID in children. The grants described in the legislative text would be helpful to facilities researching and treating pediatric Long COVID, as well as other multidisciplinary Long COVID clinics.

Disparities in Long-COVID: The language on studying disparities in Long COVID is important, and AAPM&R is appreciative of its inclusion. We believe finding disparities in Long COVID can illuminate disparities in health care more broadly. AAPM&R worked closely with the COVID Health Equity Task Force and supports many of the recommendations included in their final report. **While this section in the legislative text is necessary, perhaps it would be effective to include a reference to the Task Force's report to ensure that this work is not duplicated and is, instead, efficiently applied to help those who need access to Long COVID care and are currently unable to adequately access it.**

Education and Awareness Programs: Similarly, the text on education and dissemination of information with respect to long-term symptoms of COVID-19 is very important and has a connection to the COVID Health Equity Task Force's final report, which recommended a Long COVID communications campaign.[6] Again, **I encourage you to include a reference to the report to ensure that this work is not duplicated.**

I want to thank you for including this language and pointing out the importance of education in this space. AAPM&R's experience with the 35 multidisciplinary Long COVID clinics has taught us that much of Long COVID care and learning is housed in academic medical centers and larger health systems that had the resources to create these multidisciplinary models of care quickly. These clinics are very important and, while AAPM&R is in communication with most of them, there are not many nationwide. Additionally, the facilities that do exist are not accessible to everyone. For example, there are few in rural areas or in community clinics, making the dissemination of information imperative.

---

[6] Presidential COVID-19 Health Equity Task Force Final Report and Recommendations. October 2021. Recommendation 5. https://www.minorityhealth.hhs.gov/assets/pdf/HETF_Report_508_102821_9am_508Team%20WIP11-compressed.pdf

aapm&r

9700 W. Bryn Mawr Ave., Ste. 200
Rosemont, IL 60018
www.aapmr.org

PHONE 847.737.6000
FAX 847.754.4368
info@aapmr.org

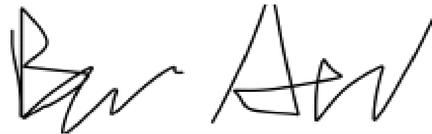
Cures 2.0 and Telehealth

AAPM&R strongly supports extension of Medicare telehealth flexibilities following the Public Health Emergency (PHE). Prior to the PHE, the definition of the term "originating site" created significant restrictions to the use of telehealth in the Medicare population. By expanding the definition of this term to include any site at which the eligible telehealth individual is located, including the home, telehealth services will become far more accessible to beneficiaries requiring an alternative to in-person services. Further, the current originating site definition requires the patient to live in a rural or healthcare professional shortage area. This definition has been overly restrictive and has limited the use and applicability of telehealth in the Medicare population. We believe telehealth has a critical place in future of physiatry and healthcare in general. AAPM&R appreciates the efforts in this legislation to improve access to telehealth following the PHE.

***

Again, I would like to thank you for your efforts to address the Long COVID crisis. Please consider AAPM&R a resource in your continued work. If there are any questions or comments, please reach out to Reva Singh, AAPM&R's Director of Advocacy and Government Affairs, at rsingh@aapmr.org or 847.737.6030.

Sincerely,



Benjamin Abramoff, MD, MS
Assistant Professor
Department of Physical Medicine and Rehabilitation
University of Pennsylvania- Perelman School of Medicine
Director of the Post-COVID Assessment and Recovery Clinic
Co-Chair of AAPM&R's Multi-Disciplinary PASC Collaborative