



December 29, 2022

Dr. Lawrence A. Tabak, Ph.D., D.D.S.  
Performing the Duties of the NIH Director  
National Institutes of Health

Dear Dr. Tabak,

We imagine you are as disappointed as many of us that the NIH appropriation for FY 2023 does not include any new funding for research on Long COVID and Associated Conditions (LCAC)<sup>1</sup>. We all were encouraged when the Administration included \$750 million for this research in the supplemental appropriation request submitted in November. That spoke to the urgent need for this funding, and it makes our disappointment in the unsatisfactory outcome for FY 2023 all the more confounding and frustrating.

The purpose of this letter is to seek information from you on what resources will be available in FY 2023 for LCAC research, including the RECOVER Initiative, in the absence of new appropriations.

As you know, the most recent CDC findings indicate that nearly 30% of people with a COVID-19 infection experience Long COVID. Nearly one in five people with LC are forced to severely limit their daily activities because their symptoms are so debilitating.<sup>2</sup> Recent studies place the economic cost of LCAC at \$3.7 trillion, with up to four million people being kept out of the workforce because of LC.<sup>3</sup>

We know you are also aware of how central NIH is to the “national, U.S. government-wide coordinated, action-oriented approach” that the Administration has

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<sup>1</sup> The term LCAC refers to the post-viral illnesses that often define a patient’s experience of Long COVID, including but not limited to postural orthostatic tachycardia syndrome (POTS) and other forms of dysautonomia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and mast cell activation syndrome (MCAS).

<sup>2</sup><https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>

<sup>3</sup><https://nihcm.org/publications/long-covid-new-research-and-the-economic-toll>

stated “is urgently needed” to advance research on Long COVID.<sup>4</sup> As Long COVID patients and advocates, we appreciate how this underscores the urgency of identifying resources to support additional research as soon as possible. We must avoid the uncertainties of waiting until the next budget cycle – which would likely delay progress on trials and treatments for at least a full year. That kind of delay would further damage the economy and exacerbate labor shortages, and would devastate the health and spirit of the millions already living with LCAC.

Although the recently-passed appropriation does not provide funding specifically for LCAC research, it does provide flexibility for NIH to transfer funds between appropriations. Even though these transfers are limited to 1% of the appropriation, this flexibility could provide up to \$475 million for LCAC research within the agency’s total appropriation of \$47.5 billion. While this would still fall short of the \$750 million that had been requested, it would nonetheless have a major impact. We urge you to consider exercising this authority in FY 2023 to support LCAC research. If you are not considering the use of this authority for this purpose, please share your reasoning with us.

Moreover, we know that these activities can be supported within the base budgets of the participating institutes: For FY 2023, the combined budget of the Office of the Director and the three lead Institutes (NHLBI, NIAID, and NINDS) is close to \$20 billion. At the meeting of the Advisory Committee to the Director earlier this month, you stated that research on Long COVID is NIH’s highest priority. We are therefore interested in learning how that prioritization will influence the deployment of these funds in FY 2023. Please share how you will be directing your own office and the Institutes to support LCAC research in FY 2023.

Finally, we are interested in any steps you are able to take in conjunction with the HHS Secretary to identify additional resources to support these efforts in FY 2023. This could include working with the HHS to identify other sources of funds or utilizing funds remaining from prior-year appropriations, such as funds provided by the American Rescue Plan.

Thank you for your attention to this very concerning situation. The outcome of the FY 2023 appropriations process is understandably a major disappointment to us all. We hope now, with your leadership, that sufficient funding can be identified to support a robust and productive level of investment in LCAC research for the remainder of this year and beyond.

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<sup>4</sup><https://www.covid.gov/assets/files/National-Research-Action-Plan-on-Long-COVID-08012022.pdf> (pg 6)

We would be happy to discuss the importance and urgency of this funding in greater detail at your convenience.

Sincerely,

The Long COVID Alliance

Solve M.E. Initiative  
COVID-19 Longhauler Advocacy Project  
Dysautonomia International  
Patient-Led Research Collaborative  
Body Politic  
Pandemic Patients  
Visible Health, Inc  
Massachusetts ME/CFS & FM Association  
HealthyWomen  
Minnesota ME/CFS Alliance  
COVID Survivors from Texas  
The Northern Virginia ME/CFS, Fibromyalgia, and Orthostatic Intolerance Support Group  
Responsum Health  
Purpose-Filled Solutions and Evolutions, LLC  
Support Fibromyalgia Network  
ME Action Network  
JDS Group  
Marked By COVID  
Science for ME  
Wail of a Tale Productions  
American CryoStem  
Indivisible, Saint Paul  
Long COVID Research Initiative

The Undersigned Individuals

Holly Lindsey	Alexis Heidenberg	Perry Norton
Dee Halzack	Allison Towle	Phil Chernin
Amy Siniscalchi	Amanda Simson	Rachel Robles
Emily Wilkinson	Amanda Weiser	Resia Pretorius
Amanda Mathiesen	Amy Engebretson	Rivka Solomon
Kimberly lane	Amy L. Gibbons	Roger Kulp
Leah Williams	Amy Welsh	Ruth McCrea
Ashley Michels	Andrew Rosenberg	Ruth Weissenborn Brannan, PhD
Marty Stephenson	Angelia Stone	Ryan Prior

Heather McCrea	Anna Kern, MSN, APRN, FNP-C	Sara Davis
Mike Heidenberg	Aris Georgakakos	Sara Goldsmith
Shari Boxer Baker	Arthur Mirin	Sarah Hamilton
Alexis Heidenberg	Barry Horn	Sarah Lee
Sara E. Blaszak	Brenda Shepherd	Siobhan Bligh
Whitney Fox	Brian Shiell	Sue Taylor
Lisa Geiszler	Catherine Milon	Susan Lyon
Dr. Susan Heffley, MD	Catherine Romatowski	Thomas Graziano
Stephen Smith	Charlene Evans	Tina Pham
Janet L. Plotkin Bornstein, PhD	Chris Begley	Tracy Clagett
Leslie G. Fleet	Christopher Maddison	Travis Hardy
Michael Goldsmith	Colleen Jordan	Viana Mora
Kimberly Mallo	Craig Golden	Billy Hanlon
William Hagedorn	Cynthia Preston	Brian Shiell
Dr. Susanne Young	Dr. David M. Parrack	William Williams
Edward Jamieson	Dr. Evelyn Rappoport	James House
Selene Seltzer	Dr. Vanessa Svihla	Andrew Rosenberg
Nansy Mathews, CRNP	Elaine Cooke	Harry Leeming
Dr. Vanessa Svihla	Elizabeth Jimerson	Kellyann Wargo
Courtney Barry	Elly Brosius	Lauren Nichols
Chanis M. Mercado Olavarria	Emily Taylor	Marty Pack
Amelia McKeithen	Eric Kennedy	Andrew Flosdorf, MPH, SSBB
Hope Shotwell	Eva Nordhauser	Dr. Gloria M Trujillo, MD
Julie Lamarche	Francine Bouchard	Ronald Deschenes
Andrew Tumminia	Hannah Cronic	Orlando Coreas
Kristi Schiroo	Hannah Rice	Suzanne Wheeler
Damali Dunlap	Heather Sohl	Andrea Joliat
Katherine Montwieler	Hope Shotwell	Sidharth Shah
Melissa Talwar	James McCrea	Linda Difelicianantonio Rocca
Christine Jamieson	James Woolley	William Muscarella
Donna Gulyas	Jessica Lamb	Paul Walters
Tracy Clagett	Jim Caroompas	Maya Lea
Catherine Milon	Joel Ratliff	Maya Rossignac-Milon
Dr. Evelyn Rappoport	John Amodio	Megan Cramer
Charlene Evans	John L. Simson	Melinda Lipscomb
Carlin DeCato	Joseph F. Heisler, Jr.	Michael Warszawski

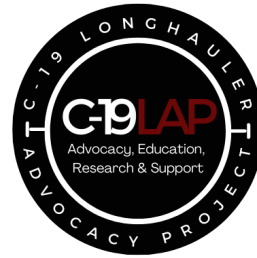
Jill B. Van De Water	Julia Watson	Mike Heidenberg
Laura Overand	Kathleen A. Fahey	Miranda Erlanson
Kimberly Goodwin	Kathy Deschenes	Miriam McCrea
Rachel Robles	Kellyann Wargo	Miriam Schoop
Michelle Bullock	Keri Kae Almstead	Morgan Baker
Kelly Keeney	Kim Ouellette	Nancy Perez
Nancy Perez	Kimberly Burnette	Nick Harrold
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Leticia Jones	Kristine Chapman	Robert Jacobs
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Danielle Levy	Laia Camins	Leslie Heemsbergen
Christine Reeves	Laura Smalec	Carol Thong
Amy Welsh	Lauren Osuch	Phil Chernin
Dr. Audrey Scanlan-Teller, PhD	Laurie Beth Koller	Wachuka Gichohi
Chris Cowman	Lee Schafer	Chris Begley
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Kyle Robinson	Patricia L. Bloom-Harrell	Cait Salinas
Rachel Bishop	Bridget Collins	Alexis Misko
Yuvonne Allison	Samantha Kutowy	Alexandra Claire Tucker
Karen Leppo	Ravi Veriah Jacques	Maria Luz Balcarse
Heather Salamay	Douglas F. Owen	Laurie Bedell

CC:

Adm. Rachel Levine, MD, Assistant Secretary for Health  
 Dr. Tara Schwetz, PhD, Acting Principal Deputy Director  
 Dr. Gary Gibbons, MD, NHLBI Director  
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 Ms. Adrienne Hallet, Associate Director for Legislative Policy and Analysis  
 Mr. Neil Shapiro, Associate Director for Budget  
 Ms. Shalanda Young, Acting Director, Office of Management and Budget  
 Mr. Christopher Spiro, Director of Health Programs, Office of Management and Budget



Solve M.E.



DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



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RESEARCH  
COLLABORATIVE**



**PANDEMIC  
PATIENTS**

**visible.**



**healthy  
women**  
informed. empowered.



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**Purpose-Filled  
Solutions &  
Evolutions™**



**SUPPORT  
FIBRO**



**jds**  
GROUP  
PUBLIC RELATIONS



**Science  
for ME**



**AMERICAN**  **CryoStem®**

  
**LONG COVID**  
RESEARCH INITIATIVE