



Solve M.E.

Rochelle P. Walensky, MD, MPH
Office of the Director
Centers for Disease Control and Prevention (CDC)
1600 Clifton Road, NE
Atlanta, GA 30333

January 31, 2022

Re: Support for Congressional Request to Report Findings on prevalence of Long COVID

Dear Director Walensky,

On behalf of the Solve ME/CFS Initiative (Solve M.E.), the undersigned organizations, and concerned community members, I am writing in support of Representatives Ayanna Pressley and Don Beyer's request for the CDC to publicly report and share disaggregated demographic data and findings on the prevalence of Long COVID. This data will be critically important to shaping future Long COVID and pandemic preparedness policies and should be made publicly available.

There are public data available regarding the demographics and prevalence of acute SARS-CoV-2 infections. Research has shown that people of color have borne a disproportionate burden of COVID-19 pandemic¹. Racism and discrimination play major roles in patients' ability to access care. They create barriers, economic cost, and erode potential positive health outcomes². Additionally, adverse socio-economic conditions, such as income and socioeconomic status, social isolation, education, food and physical security, and housing status, increase the likelihood of both COVID-19 infection and poor COVID-19 disease or recovery outcomes³.

However, we do not yet have comparable public data available for key demographic breakdowns regarding Post-Acute Sequelae of SARS-CoV-2 infection (PASC). The WHO estimates that 10% to 20% of COVID-19 patients experience lingering symptoms for months following infection⁴. As outlined in Rep. Beyer and Pressley's congressional letter, this demographic information is needed to understand the scope of this secondary health crisis and help direct Congressional action, including funding for future research and patient support initiatives. This data is also key to our work as organizations seeking to support communities who are more vulnerable to Long COVID.

¹ Sze, S., Pan, D., Nevill, C., Gray, L., Martin, C., & Nazareth, J. (2020, November 12). Ethnicity and clinical outcomes in COVID-19: A systematic review and meta-analysis. *EClinicalMedicine*. <https://doi.org/10.1016/j.eclinm.2020.100630>

² Artiga, S., Corallo, B., & Pham, O. (2020, August 17). Racial Disparities in COVID-19: Key Findings from Available Data and Analysis. Kaiser Family Foundation. <https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-covid-19-key-findings-available-data-analysis/>

³ Upshaw, T., Brown, C., Smith, R., Perri, M., Ziegler, C., & Pinto, A. (2021, March 31). Social determinants of COVID-19 incidence and outcomes: A rapid review. *PLOS*. <https://doi.org/10.1371/journal.pone.0248336>

⁴ A clinical case definition of post covid-19 condition by a Delphi Consensus, 6 October 2021. World Health Organization. https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1. Published September 6, 2021. Accessed January 25, 2022.

In order to identify and remove barriers to adequate and equitable care, we need to understand the extent of this post-infection condition across diverse populations. This includes race, ethnicity, gender, age, co-morbid conditions, and socioeconomic status.

We echo Representatives Ayanna Pressley and Don Beyer's request to publish findings on race, ethnicity, age, gender, previous disability, and other demographic characteristics. We appreciate your leadership and responsiveness to the needs of our communities.

Thank you for your attention to our request.

Sincerely,



Oved Amitay
President and CEO
Solve M.E.
OAmitay@solvecfs.org

In partnership with:

Pandemic Patients
CircumSTANCE : MIS-C Awareness
Long Covid Families
Utah COVID-19 Long Haulers
The Ehlers-Danlos Society
Marked By Covid
Massachusetts ME/CFS & FM Assoc.
Vall d'Hebron Hospital Research Institute (VHIR)
Massachusetts MECFS & FM Association
Simmaron Research

Adam portzel, Small business owner, VA
Adina Gerver, NY
Adrian Murphy, OH
Adrienne Gomez, NM
Alan Gurwitt, M.D., Past President,
Massachusetts ME/CFS & FM Association, MA
Alex Dewel , MO
Alicia Ussery, AZ
Alysa D, IN
Alyssa Osberg, CA
Amanda Kreiss, PA
Amelia Edgeland, NM
Amy DeWinter, Founder, Ascenda Medical, NC

Amy Hackley, AZ
Amy Jeffreys , VA
Amy Rengo, MI
Angela Grainger ,Disabled Myalgic
Encephalomyelitis, CA
Angela Griffith, WI
Angela Picozzi, MA
Angi Perkins, TN
Ann Cavanagh Kramer, MN
Ann McDonald, MO
Ann Wallace, Vice President, Covid-19
Longhauler Advocacy Project / Associate
Professor, New Jersey City University, NJ
Anne Anderson, NE
Anne Kennedy,

Anne Mattison , VA
Anne Pfluger, TX
Anne Walker , IL
Annegret Daiss , CA
Annie, IL
Annie McGarry ,Long covid sufferer, NC
Anthony L. Komaroff, MD, Professor of
Medicine, Harvard Medical School, MA
Arthur Johnson , MA
Ashley Hultman, TN
Ashlyn Beam,My mom has mecfs/pots
syndrome , TN
Azita Simler, WA
Barbara Kyne, CA
Barbara Lubash, CA
Ben DeGarmo, CA
Benjamin Cruz, FL
Bernadette Sullivan, CO
Bert Forbes, CA
Bethany Eisenberg, MA
Bethany Meier, CO
Bill Bradford, TX
Bon Marie Munier, Sick of ME/CFS, CA
Bonnie Mayer, FL
Brenda J Mendes, MO
Brent Merritt, VA
Brian Shuell, MI
Bridgett Monville , WI
Brittany Porter, NY
Bryn forbes, CA
Carol Farrell, OK
Carol Peterson, CA
Carolyn G Koehler, WA
Carolyn Werner, PA
Catherine McGinley , TX
Catherine Meyer, CA
Cathleen Jones, CA
Cecelia Noel, Retired Executive Director, OR
Cecilia S Creighton Johnson, NH
Charles Rubu, GA
Charles W. Lapp, MD, Physician / Medical
Director, NC
Charlette, KY

Charmian Proskauer, ME/CFS advocate and
caregiver, MA
Cheryl Dzubak, NJ
Cheryl Viering, NC
Chris Jestis, NC
Chris Pfeiffer,Sufferer, TN
Christie Cooper, CT
Christie Stutes, GA
Christine Cowgill, MA
Christine Jamieson, Disabled with long covid for
19 months, DC
Christopher Coughlan, PA
Christopher Walton, IL
Colette Christianson, VA
Colleen Martin, CA
Corinne , CO
Cynthia Adinig,Long Covid Advocate, VA
Cynthia D. Blackmon, SC
Cyrano Menefee , OH
Dan, HI
Danielle warner, MI
David Livengood, NC
David Maughan, Professor Emeritus, Molecular
Physiology & Biophysics, WA
David Morton, WA
Dawn Holt, FL
Dawn Marie Tabery, UT
Dawn Polny, CA
Deana Vander Aarde, MN
DeAnna Smith,LPN, NJ
Deborah Donahoe ,RN, ID
Deborah Eckstein, FL
Deborah Gray, IL
Deborah Neulander, WI
Deborah Temple, CA
Debra Duffy-Smet, MN
Debra Lacy , IN
Deliah Doolan , CA
Denise Tirimacco, MN
Dennis Bushey, MA
Denyse Hilsby, FL
Derek Racine, CA
Destiny Brown, CO
Diane Acebedo, Lvn, CA

Dion Frederico, Mom, NV
Donald Fraser, VA
Donald Lucas, Deputy Director Lawrence
Berkeley National Laboratory (retired), CA
Donna Fernstrom, VA
Donna Gulyas, FL
Donna Miller, MA
Donna Robillard, OTR, MI
Doris E. Sanders, Long time ME/CFS person, CO
Dr. Ellen Wolk, MA
Dr. Jeffrey Blum, MD, NC
Dr. Lauren Bedrosian, MA
Dr. Lori Paporello, MA
Dr. Marcia, MA
Dr. Margaret Duesenberry, MA
Dr. Mary Risinger PhD, OH
Dr. Philip Buttaravoli, M.D., FL
Dr. Stephen Holka, IN
Dr. Suzette Bishop, TX
Dr. Victoria Boies, IL
DS George-Jones, GA
Elaine, FL
Elisa Emmer, NJ
Elizabeth Hostas, TX
Elle Seibert, CA
Ellie Strand, WI
Emily Dickinson-Adams, CT
Emily Fraser, CA
Emily Raffety, MO
Emily Wilkinson, DC
Emmanuelle Marquis, Person with long COVID,
MI
Esther Dyson, health advocate, angel investor,
NY
Fern Mulholland, FL
Fern Oppenheim, NY
Gail cooper, CA
Galia Shapiro, AZ
Garret Chambers, TX
gary shapiro, SC
Gayle Rice, OH
Gelinda Kay Brown, daughter has mecfs and
pots syndrome, TN
Gina Tremper, ME/CFS patient, CA
Glenn Tucker, MI
Gloria Harbin, NC
Gloria Winscott, AZ
Grace Terzian, VA
Greg Barbash, NY
Hallie Lene, SD
Hannah Rice, CO
Hap tively, NY
Henry Scott, CA
Herman Ryan Strumpf, PC-s, Licensed
Supervising Professional Counselor, IN
Holly Heiman, CO
Holly Lindsey, AR
Jacqueline Evangelista, OH
Jade Tumazi, CA
Jakob Kempema, Advocate, UT
james e faber, NC
Jamie Crull, IL
Jan Rainier, MA
Jane Jakoubek, IA
Janet Feldman, NC
Janet Lynn Walker, IN
Janet Molina, OR
Janet S Jefferson, FL
Janet Yates, WA
Jason Reyes, CFS/M.E. Sufferer, NJ
Jean E. Claussen, IL
Jeanne Baker, PA
Jen D Lanzieri, OH
Jenna Peeler, VT
Jennifer, IL
Jennifer Farron, NY
Jeremy Barth, NY
Jeremy Hagler, wife has mecfs/pots syndrome,
TN
Jeri Holmes, MD
Jesse, NY
Jessica Christiansen, CA
Jessica Lasyone, IL
Jessica Sands Carter, NV
Jo Jenkins,
Joan Furst, CA
JOANN GREEN, CO
Jodi Center, VA

Jodi Diffenderfer , GA
Jodi Gray, NH
Joe Galliani,President, Mr. Joe's Really Big
Productions, CA
John and Kristi Mitchell , OH
John Bump, IL
Jonathan Hawkins,
Jonathan Seiler, OH
Josephine O'Connor , NC
Joyce Alessi,LCSW, BCD, CA
Judy Platt, MA
Julie Salamon, CA
Julie Smith, AL
Juliet Hattersley, CA
Karen Bowman, CA
Karen Clinton, MN
Karen Humsey, FL
Karen Lykke, VA
Karen M Scott, CA
Karen Nohelty , CA
Karen Thaw, MA
Kari Merner , WA
Karman Kregloe, CA
Katherine Allen, Registered Nurse, TX
Katherine Cochrane, retired educator, MO
Kathi Cavanagh, Citizen, mother, grandmother ,
MN
Kathleen Flaherty ,
kathleen steele,LCSW, CA
Kathryn ,
Kathryn Varga, CO
Kaye-Ailsa Rowan, CA
Ken Fraser, NM
Kerri McCrossen Morrison ,BSN, RN, CCTC,
Longhauler and LCA member , LA
Kim Blend, OH
Kim Critelli , OR
Kim G Carlson, MN
Kim Visconti, NJ
Kimberly Hicks, PA
Klara, OR
Klaus Fechner , CA
Kristin Chambers, WA
LaSandra Rodriguez, OR

Lauren W, WA
Laurie Wilson , NY
Leah Williams,Advocate, MA
Lee Simler, WA
Lesa Schultz ,Ceo/ long covid patient, TN
Leslie Nassau, NJ
Lia Di Stefano, NJ
Lianne Beyerl, MN
Linda J Ferguson, MD
Lisa, CA
Lisa Barrett, MI
Lisa Espiritu, CA
Liza Fisher, TX
Lori baker-sperry,Teacher, IL
Lori J. England,ME/CFS Advocate, VA
Lori JungbluthRoss , MI
Lori Madeira , CA
Lucy M Crozier, PA
M. GÓMEZ ,LMBT, manual therapist,
kinesiologist, NC
Madeline Berger, CA
Manuel Kreft, DE
Margaret H Manchester,
Margaret Tarampi, CT
Marie Addvensky, NJ
Marie Moroney, IL
Mark Diffenderfer, GA
Marty Stephenson, Patient, OH
Mary Ann Sabia, MA
Mary O'Connor, NC
Mary Southworth , MA
MaryAlice McNamara, MD, OR
Matthew Cavanagh, IL
Maureen Donoghue, MI
Megan Kelly Neil, CA
Melinda Lipscomb,ME/CFS patient and
advocate , MD
Melissa M Rotella, NJ
Melissa OBrien, VA
Melissa Salus, LA
Mia Nielsen , PA
Michele Lyon , WA
Michele R. Renaud, NY
Michelle Sipl, CA

Miriam , NC
 Miriam Queenen , MN
 mitchell schoen, OR
 Nancy Gillis, CA
 Nat Fraser, CO
 Natalie Kuc, IL
 Nathan Simler, WA
 Nathan Spencer, MA
 Nora Lieberman ,Patient, DC
 Pacey B,
 Pam Day, TX
 Pam Shank, GA
 Pamela DeRaddo, NY
 Pamela Kavelman , PA
 Pat D. Sonnett, FL
 Patricia Ream, PA
 Patty Janecek,person with ME/CFS - 25 years,
 WY
 Paula Frighetti , AZ
 Peter Hanauer , CA
 Phillip J. Anglin, GA
 phyllis searby, NJ
 Priscilla Hardy, MI
 PSchnur, OR
 Rachael Carder, MN
 Rachel Kantor, MT
 Rachel LeJuerrne, KS
 Rebecca Knittle, MN
 Rebecca Mata, CA
 Rebecca Redner, MA
 Rhonda Smith, IN
 Rich Caloggero, MA
 Richard Zachary,Ph.D., NJ
 Rivka Solomon , MA
 Robert Haynes,Professor of English, TX
 Robert P. Jacobs, SC
 Robert Riemensnider, SC
 Robert Wilson, CA
 Robin Scott,Parent, CA
 Robin Wagher, DC
 Roger J. Canders, NY
 Rosalee Benelli,M.A., LMFT, CA
 Rowan Reyes, NY
 Rowena Chodorow, TX
 roxanne hewitt, NV
 Ruchi Watson , UT
 Ruth Feiertag, CO
 Sage Wiess, TX
 Sally Feinberg, Retired RN, NY
 Sally Shurter, CA
 Samantha Hodge-Williams, MD
 Sandra Dixon, NY
 Sandra S. Jacobs, SC
 Sara D Kelly, VA
 Sara Vadgama, CA
 Sarah Ingram, OR
 Sarah Robinson, FL
 Saralee Johnston, UT
 Shari Burns, TX
 Sharon , IL
 Sharon Addvensky , NJ
 Sheila LeMaire, TN
 Stacie Ballweber, OH
 Stacy Abrams ,
 Stacy Cooper,Long Covid Patient, ME
 Steana Ebbers, WA
 Stephanie Chou,Registered Nurse, WA
 Stephanie Thorne , OR
 Steven Freedman , MN
 Susan Barbash, NY
 Susan Buckley, MA
 Susan Griffin ,Long covif, CA
 Susan L Palumbo, GA
 Susan Pantell, TX
 Susan Pierres , FL
 Susan VandeBrake, MI
 Susan Werbe,Educator of Diverse Learners &
 Exceptional Needs, IN
 Suzanne Bonta , CA
 Suzanne Elliot,patient / advocate , VA
 Tami Galt, CA
 Tammy Dillon, FL
 Tanya Hovey, UT
 Terry Gilmete,Patient who has suffered for 35
 years with post-viral fatigue syndrome (Myalgic
 Encephalomyelitis/Chronic Fatigue), CA
 Theresa Carlus, IL
 Thomas Schmidt, MD,Physician, MN

Timothy Sullivan, FL
Todd Pryor, MI
Tom Groff, NY
Toni, GA
Toni E. Lesowitz, PhD, IL
Tori Markwalder, MA
Traci Robinson, OK
Tracy Duvall, MD
Tracy Hagler, Licensed Practical Nurse and an
MECFS/ POTS syndrome Patient, TN
Tracy Waechter, OR
Tree Delfin, NY
Trisha DeGroot, TX
Valerie Wilson ,
Vicki Lucas, CA
Victoria Beltz, FL
Vijay Iyer, Ph.D., MA
Virginia Naef, WA
Whitney Fox, MD
William Hanlon, Patient Advocate, MN
William Squier, CA
Wilma Louise Ingram, OR
Yuko Hanakawa, Clinical Psychologist, NY
Bonnie A., A person living with Long COVID since
February 2020
Frøydis Lilledalen, Psychologist
Luc Van de Velden, patient
Sue Bolton
Nicole Keefler
Heidi Stafford
Jane Seary
Linda Gowman
Stephanie Nimmo
Alisa
Susanna Agardy
Elizabeth Edwards
Daniel Smalley
Dr. Belinda Rowland
Sandra Mayor
Karen Dodsworth
Stephan Oberg
Claire Knights
Anna Biggs
Mandy Moore

Steve
R Catania
Simon D
Maggie
Audrey
Margo
Bruce
Pati
Jehu
Meredith
Margie
Erica
Ursula
Sharon
Lori
Mallory
Kristyn
Sharon
Michael
Anne
Keren
Julia
Xena
Donna
Ninane
Beverly
Robert
Raven
Michele
Patrick
Sarah