

August 23, 2021

The Honorable Charles Schumer
Senate Majority Leader
S-221, U.S. Capitol Building
Washington, DC 20510

The Honorable Nancy Pelosi
Speaker of the House
H-232, U.S. Capitol Building
Washington, DC 20515

The Honorable Mitch McConnell
Senate Minority Leader
S-230, U.S. Capitol Building
Washington, DC 20510

The Honorable Kevin McCarthy
House Minority Leader
H-204, U.S. Capitol Building
Washington, DC 20515

Dear Majority Leader Schumer, Minority Leader McConnell, Speaker Pelosi, and Minority Leader McCarthy,

As Congress considers policies related to workers and families in the coming months, we write today to urge lawmakers to authorize and fund a national paid family and medical leave program that includes paid leave benefits for individuals with serious illnesses and health conditions and caregivers.

Our organizations were pleased that temporary provisions related to paid medical leave were included in the Families First Coronavirus Response Act last year, but much more needs to be done. It is important to ensure that all U.S. workers have access to paid leave benefits when they have a qualifying need so that access to paid leave no longer depends on an individual's employment, or the nature of their job.

The 29 undersigned patient advocacy and partner organizations are joining together to urge lawmakers to develop a new national paid family and medical leave program with the needs of the patient community in mind. We represent caregivers and patients with serious illnesses and conditions including heart disease, cancer, ALS, muscular dystrophy, epilepsy, AIDS and HIV, cystic fibrosis, hemophilia, Alzheimer's, and many others.

The availability of paid family and medical leave for people with and caring for individuals who have a serious illness or health condition is vital, as treatment for and recovery from serious illnesses and conditions are often difficult and time consuming. The flexibility to balance treatment and employment is essential for patients and caregivers. For example, multiple studies show that cancer patients and caregivers who have paid leave have higher rates of job retention and lower rates of financial burden than those who do not have access to paid leave.^{1,2,3} Not all patients or caregivers have access to paid family and medical leave, and without it they risk financial hardship or not getting the care they or their loved ones need.

¹ Veenstra CM, Regenbogen SE, Hawley ST, Abrahamse P, Banerjee M, Morris AM. Association of Paid Sick Leave With Job Retention and Financial Burden Among Working Patients With Colorectal Cancer. JAMA. 2015 Dec 22 29;314(24):2688-90. doi: 10.1001/jama.2015.12383. PubMed PMID: 26717032.

² Veenstra, C.M., Abrahamse, P., Wagner, T.H., Hawley, S.T., Banerjee, M. & Morris, A.M. (2018). Employment Benefits and Job Retention: Evidence Among Patients With Colorectal Cancer. Cancer Med. 2018 Mar; 7(3): 736–745. doi: 10.1002/cam4.1371.

³ ACS CAN. Paid Leave is an Important Component of Cancer Care for Working Patients, Survivors and Caregivers. October 23, 2020. <https://www.fightcancer.org/sites/default/files/Paid%20Leave%20External%20Factsheet%20Final%2010-23-20.pdf>

About one-fifth of workers in the United States have access to employer-paid family leave⁴ and only two in five have access to short-term disability insurance through their jobs that allows them to receive partial pay while they recover from their own serious health issue.⁵ Fewer than 60 percent of workers qualify for job-protected, unpaid leave under the Family and Medical Leave Act (FMLA), and workers of color, low-wage workers and single parents are disproportionately excluded.⁶ People of color and with lower incomes are also disproportionately impacted by many of the diseases our groups represent – meaning the very patients who are more likely to need to use paid family and medical leave are the ones least likely to have access to it.

Our organizations have long fought to ensure that patients have access to care to treat their serious illnesses and health conditions. Being able to take time off work is fundamentally an access to care issue, and our current patchwork system of paid and unpaid leave forces some patients and caregivers to choose between treating their illness and keeping their job or having enough income to survive – while also exacerbating health inequities.

For these reasons we urge you to enact a national paid family and medical leave program that includes paid leave for patients and caregivers and is adequately and sustainably funded. Furthermore, it is imperative that the program is authorized and funded beyond the short term and that seriously ill patients and their caregivers are able to rely on the program to access needed care on an ongoing basis, for a meaningful number of weeks or intermittently when they need it.

Thank you for considering our requests. If you have any questions or would like to talk with our representatives, please direct your staff to contact Stephanie Krenrich at the American Cancer Society Cancer Action Network at stephanie.krenrich@cancer.org.

Sincerely,

Academy of Oncology Nurse & Patient Navigators
(AONN)
The AIDS Institute
Alliance for Aging Research
Alpha-1 Foundation
ALS Association
American Cancer Society Cancer Action Network
American Heart Association
The Arc of the United States
Association of Community Cancer Centers (ACCC)
Association for Clinical Oncology
Black Women's Health Imperative
Cancer Support Community
Cervivor, Inc.
Cystic Fibrosis Foundation
Epilepsy Foundation

Fight Colorectal Cancer
Hemophilia Federation of America
LatinosAgainstAlzheimer's Network
Mended Hearts & Mended Little Hearts
Muscular Dystrophy Association
National Alliance for Caregiving
National Alliance on Mental Illness
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Patient Advocate Foundation
Pulmonary Hypertension Association
Susan G Komen
UsAgainstAlzheimer's
WomenHeart: The National Coalition for Women
with Heart Disease

⁴ Table 31. U.S. Bureau of Labor Statistics. National Compensation Survey: Employee Benefits in the United States, March 2020. September 2020. Bulletin 2793. <https://www.bls.gov/ncs/ebs/benefits/2020/employee-benefits-in-the-united-states-march-2020.pdf>

⁵ Table 16. U.S. Bureau of Labor Statistics. National Compensation Survey: Employee Benefits in the United States, March 2020. September 2020. Bulletin 2793. <https://www.bls.gov/ncs/ebs/benefits/2020/employee-benefits-in-the-united-states-march-2020.pdf>

⁶ Abt Associates, prepared for the U.S. Department of Labor. Employee and Worksite Perspectives of the Family and Medical Leave Act: Results from the 2018 Surveys. July 2020. https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/WHF_FMLA2018SurveyResults_FinalReport_Aug2020.pdf