

October 12, 2021

President Joe Biden  
The White House  
1600 Pennsylvania Ave., NW  
Washington, DC 20500

Dear President Biden,

As your Administration and Congress continue to negotiate the budget reconciliation package, we write today to urge you to include a national paid family and medical leave program that includes paid leave for individuals with serious illnesses and health conditions and caregivers.

While we understand that difficult decisions need to be made with regards to the reconciliation package, individuals with serious illnesses and caregivers are counting on you to help ensure they do not have to choose between treating their illness or having enough income to survive.

The 20 undersigned patient advocacy and partner organizations represent patients with serious illnesses and conditions including cancer, ALS, muscular dystrophy, epilepsy, hemophilia, Alzheimer's, Long COVID and many others. While policymakers debate this legislation, every day new patients are diagnosed with these diseases – and patients and their families are faced with questions about how to balance work, treatment, and finances. While you are negotiating budget targets in the billions, we ask you to remember the working patients and caregivers who are struggling to balance their own budgets as they treat or recover from their illness, or give care to loved ones, and try to still earn a paycheck.

The availability of paid family and medical leave for these people 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.<sup>1,2,3</sup> Research demonstrates that paid family leave helps Alzheimer's patients and their caregivers better navigate complex medical care.<sup>4</sup> 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.

According to the Bureau of Labor Statistics' National Compensation Survey on employee benefits, in early 2021, 23% of private-sector workers had paid family leave through their jobs – leaving more than 88 million workers without paid family leave to care for a loved one.<sup>5</sup> Only 42 percent of workers had access to personal medical leave through an employer-provided short-term disability insurance policy.<sup>6</sup> 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.<sup>7</sup> 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.

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](mailto:stephanie.krenrich@cancer.org).

Sincerely,

Alliance for Aging Research  
ALS Association  
American Cancer Society Cancer Action  
Network  
American Heart Association  
Association of Oncology Social Work  
Cancer Support Community  
Child Neurology Foundation  
COVID Survivors for Change  
Epilepsy Foundation  
Friends of Cancer Research

Hemophilia Federation of America  
Muscular Dystrophy Association  
National Alliance for Caregiving  
National Coalition for Cancer Survivorship  
National Organization for Rare Disorders  
National Patient Advocate Foundation  
Susan G. Komen  
Triage Cancer  
UsAgainstAlzheimer's  
WomenHeart, The National Coalition for  
Women with Heart Disease

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<sup>1</sup> 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.

<sup>2</sup> 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.

<sup>3</sup> 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>

<sup>4</sup> UsAgainstAlzheimer's. Supporting Family Caregivers Providing Alzheimer's and Dementia Care [https://www.usagainstalzheimer.org/sites/default/files/2018-09/A New Frontier In Paid Leave.pdf](https://www.usagainstalzheimer.org/sites/default/files/2018-09/A%20New%20Frontier%20In%20Paid%20Leave.pdf). September 2018

<sup>5</sup> U.S. Bureau of Labor Statistics. National Compensation Survey: Employee Benefits in the United States, March 2021. September 2021. <https://www.bls.gov/ncs/ebs/benefits/2021/employee-benefits-in-the-united-states-march-2021.pdf>

<sup>6</sup> Ibid.

<sup>7</sup> 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/WHD FMLA2018SurveyResults FinalReport Aug2020.pdf](https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/WHD_FMLA2018SurveyResults_FinalReport_Aug2020.pdf)