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UNITED STATES DISTRICT COURT
NORTHERN DISTRICT OF CALIFORNIA
SAN FRANCISCO DIVISION

ARGHAVAN SALLES; ABIGAIL HATCHER; ANDREA ROSSO; ANN D. COHEN-WILSON; DOLORES ALBARRACÍN; HEIDI MOSESON; JADE PAGKAS-BATHER; JONATHAN KYLE DAW; KATIE EDWARDS; KELTON MINOR; MICHAEL D. GREEN; SARA JACKSON; SUZANNE BELL; JORDAN DOE 1; JORDAN DOE 2; JORDAN DOE 3; and JORDAN DOE 4, *on behalf of themselves and all others similarly situated,*

Plaintiffs,

v.

NATIONAL INSTITUTES OF HEALTH; JAY BHATTACHARYA, *in his official capacity as Director of the National Institutes of Health*; UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES; ROBERT F. KENNEDY, JR., *in his official capacity as Secretary of the United States Department of Health and Human Services*; and UNITED STATES DOGE SERVICE,

Defendants.

Case No. 3:26-cv-10510-SK

DECLARATION OF SARA JACKSON

* Application for *Pro Hac Vice* Admission Forthcoming
** Out-of-State Licensee Renewal Pending

(Additional Counsel on Behalf of Plaintiffs)

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* Application for *Pro Hac Vice* Admission Forthcoming

I, Sara Jackson, declare:

1. I have personal knowledge of the facts set forth in this declaration, and if called to testify as a witness thereto, could do so competently under oath.

2. My name is Sara Jackson. I previously went by my married name "Sara Bybee".

3. I am offering this declaration in my individual capacity and not on behalf of my employer.

4. I am a Licensed Clinical Social Worker and an Assistant Professor at the University of Utah College of Nursing. My research focuses on health equity and structural determinants of health in complex care settings. Specifically, I examine how systemic barriers shape health outcomes for historically marginalized populations, with particular emphasis on dementia, palliative care and chronic illness management.

5. I earned my PhD in Nursing from the University of Utah and did postdoctoral work through the Utah Clinical and Translational Science Institute, where I investigated screening for and addressing social needs in medical settings.

6. I am widely published in top medical journals, including The American Journal of Hospice and Palliative Medicine, The Journal of Clinical Oncology, and Psychology & Sexuality, among many others.

7. I have been funded on multiple NIH awards including as a co-investigator on the following studies:

- Enhanced Digital Access to Bridge Social Needs and Reduce Health Disparities: The e-SINCERE Study. National Institute of Nursing Research (1R01NR021501/NIH; PI: A. Wallace);
- LEADing End-of-Life Dementia Care Conversations. National Institute on Aging (1R01AG069033-01A1/NIH; PI: K. Dassel);
- Intensifying Community Referrals for Health: The SINCERE Intervention to Address Covid-19 Health Disparities. National Institute of Nursing Research (1R01NR019944; PI: A Wallace).

8. These studies have resulted in multiple publications in high impact journals such as the following:

- Bybee, S. G., Clayton, J., Aruscavage, N., Utz, R., Bigger, S. E., Iacob, E., & Dassel, K. (2025). Engaging in the Life-Planning in Early Alzheimer's and other Dementias (LEAD) Advance Care Planning (ACP) intervention is associated with perceived ACP concordance and interpersonal connectedness. The Gerontologist. https://doi.org/10.1093/geront/gnaf179
- Bybee, S., Tedford, N.J., Grigorian, E.G., Luther, B., Guo, J-W., Wong, B., Diamond, L., and Wallace, A.S. (2025). Focus groups reveal how threat vigilance hinders social needs screening and referrals in the emergency department. Frontiers in Communication, Volume 10 – 2025. https://doi.org/10.3389/fcomm.2025.1558250
- Bybee, S., Sharareh, N., Guo, J-W., Luther, B., Wang, C-Y., Wong, B., & Wallace, A. (2024). A secondary data analysis of technology access as a determinant of health and impediment in social needs screening and referral processes. AJPM Focus, 3(2), 100189. doi: 10.1016/j.focus.2024.100189

9. I was funded by the Interdisciplinary Training in Cancer, Caregiving, and End-of-Life Care training program as a pre-doctoral student (National Institute of Nursing Research (T32 NR013456; MPIs: L. Ellington & K. Mooney). And I served as a graduate research assistant on the following NIH projects:

- Sexual and Gender Minority Cancer Caregivers and Hospice Team Alignment. SGM Admin Supplement, National Institute of Nursing Research (PA-17-098; NINR/1R01NR016249; PI: L Ellington);
- Cancer Caregiver Interactions with the Hospice Team: Implications for End of Life and Bereavement Outcomes. National Institute of Nursing Research (NINR/1R01NR016249; PI: L. Ellington).

10. I am also currently the Principal Investigator on an Alzheimer's Association funded study, Fostering Equitable Dementia Care for Hispanic/Latino Communities.

11. I am the recipient of the Carroll L. Estes Rising Star Award bestowed upon me by the Social Research Policy and Practice Section of the Gerontological Society of America. In 2024, I was awarded the Excellence in Research Award by Sigma Theta Tau International Gamma Rho Chapter, and in 2025 I was honored to receive a 40 Under 40 Public Health Catalyst Award from the Boston Congress of Public Health.

12. The research I conduct is important to me because it allows me to help those who have been historically under researched or who do not have the same access to resources or assistance that those more fortunate may have. Improving quality of life for individuals, families, and communities is not only fulfilling, but I feel it is my responsibility as a scientist.

13. In 2024 I was named as a PI on a R01 grant titled Developing an Inclusive Measure of Financial Hardship for People Living with Dementia and their Care Contributors. The grant has a project term of 8/15/2024 through 6/30/2029.

14. NIH grant applications are incredibly demanding. Preparing one can take months or even years. Proposals often exceed 200 pages and must make a compelling case that the health issue being studied is urgent and scientifically significant. Applicants must prove that their proposed methods are the best possible approach to solve the problem. They must also demonstrate that their team is uniquely qualified. Every application undergoes rigorous peer review by experts, and funding rates are low—especially for R01 grants, where many researchers apply multiple times before ever being funded. To ensure this proposal was a success, I devoted nearly all my working time as well as some personal time towards developing a rigorous proposal. This meant that I took time away from my young children to devote myself to this proposal. Securing a grant is not just about money—it's an indication of a project's scientific importance, methodological rigor, and real-world potential to improve public health.

15. The award focuses on the financial burdens borne by people living with dementia (PLWD) and their care contributors, with a special emphasis on the increasing diversity of older adults in the US, who may have support networks involving families of choice. My goal is to develop and psychometrically validate an inclusive measure of financial hardship for PLWD which attends to the specific disease trajectory of Alzheimer's Disease and other forms of dementia and expands the concept of family to include non-kin care contributors, thus laying the groundwork for future intervention studies

designed to reduce financial and health inequities among this population. Attached hereto as **Exhibit 1** is a true and correct copy of this R01 grant's Notice of Award (i.e., NOA).

16. During the first two years of the grant, my research team and I successfully recruited dementia professionals and experts in sexual and gender minority health to participate in a focus group. We also developed an eligibility survey to screen LGBTQ+ and non-LGBTQ+ persons living with dementia and care partners for potential participation in our other two focus groups. All three focus groups were completed as of 2026. During focus groups, we asked participants for their opinions on several dementia-related expenses to better understand which items had the greatest impact on their financial hardship and quality of life (for example, adult day care, insurance co-payments, medications). We asked participants about their experiences affording care, how that affects their psychological wellbeing, and what types of strategies they have used to navigate any financial difficulties. We have also completed interviews with participants of these focus groups to further refine our measure of financial hardship. During interviews, we asked participants for their opinions on the wording of the measure's instructions, and to identify any areas that were confusing or where the instructions were unclear. We also asked participants for suggestions on how to ensure the measure was applicable to both persons living with dementia and to care partners, as well as how to make the measure inclusive enough to capture the lived experiences of LGBTQ+ persons living with dementia and their care partners.

17. Our next steps include refining our measure based on feedback received from our interviews and testing the refined measure with a sample of thirty care partners to persons living with dementia. We will then ensure the measure is reliable by testing it with a new sample of 435 care partners to persons living with dementia, half of which will be care partners to LGBTQ+ persons living with dementia so we can ensure the measure is inclusive enough to capture the unique caregiving experiences of these individuals.

18. In 2025, I heard through my university that I should reach out to my program officer (PO) at NIH and ask to edit my public-facing grant details, including the abstract and public health relevance statement, to remove disfavored terms, to avoid the termination of my grant. While I had some misgivings about doing this, I made the changes in an effort to protect my research. Since my project is open to any person living with dementia and their care partner and not solely focused on LGBTQ+

persons, I re-wrote the public-facing abstract to reflect this fact and removed the terms LGBTQ+, sexual and gender minority, etc. The scientific aims of the study did not change at this time.

19. After making these changes, and submitting my annual progress report as required, I received a second year of funding.

20. I submitted my second annual progress report in a timely manner.

21. On May 27, 2026, I received an email from my program officer stating that "to proceed with funding consideration" I would need to renegotiate the scope of my award "to make it consistent with NIH's ongoing internal review of HHS/NIH's priorities and the alignment of awards with those priorities." Specifically, I would "need to review the current annual progress report to remove any DEI language and, if needed" adjust my budget to avoid supporting any "DEI activities [] or programs." The email indicated that I had three days to rewrite my project materials, including my project aims, which included conducting focus groups with LGBTQ+ and non-LGBTQ+ individuals.

22. I have never heard of a request to renegotiate an already-awarded grant. It is common for NIH to request changes to a research plan prior to awarding funding, but with the exception of budgetary changes, I have not heard of NIH requesting changes in agreed-upon research.

23. As I had already completed these research aims, I did not feel that I could re-write them without being dishonest about the work, so my authorized organization representative in the Office of Sponsored Projects at the University of Utah emailed my PO to state that I would not be renegotiating the scope of my work.

24. An NIH supervisory grants management specialist responded by asking "[i]f the PI is not willing to renegotiate the scope of work, will you be submitting a request for early termination?"

25. I responded that I would not; that I wanted to "continue on with the award as originally agreed upon in the notice of award I received in 2024." Upon NIH's request, my university indicated their concurrence with that decision. Attached hereto as **Exhibit 2** is a true and correct copy of this email correspondence.

26. I have not heard from NIH since. I have not received a termination notice, but I have also not received any confirmation of my third year of funding. My second-year budget ended June 30, 2026. Given my refusal to renegotiate my research aims to remove all mention of LGBTQ+ people and other

"DEI language," I expect that my project will be terminated, either through a notice of termination, a denial of my noncompetitive renewal (NCR), or through what has come to be called a "ghost termination"—when NIH does not award or deny continuation funds, but simply lets the award languish without funding.

27. I have begun planning for what I will do without the final three years of anticipated funding. I am looking for bridge funding, and trying to come up with creative ways to continue the work, but unless my NCR arrives soon, I expect to have to lay off two employees, and discontinue work on this research study. One of my employees has already accepted another job because of our lapse in funding.

28. My work relies on NIH funding, so unless this situation resolves soon, I will likely have to pivot to other areas of research, like palliative care, that are not currently disfavored by the NIH. Once I make that change it is unlikely that I will be able to restart my current work.

29. Ending work on this project means that the individuals who participated in the focus groups and cognitive interviews (those who have shared some of their most personal and painful stories related to dementia) will have to be told that their contributions will not make a difference in the lives of others in the future, as they originally were told.

30. In addition to the loss of three staff members, I have four additional co-investigators on this project, who are all losing time devoted to this project. For some, this means that a lower percentage of their time is covered by NIH funding, which could affect their requirements for receiving tenure. The loss of this funding means I will no longer manage a research lab in which I can supervise trainees, including pre-doctoral and postdoctoral scholars. Our ability to disseminate any findings from the focus groups and cognitive interviews is also affected, as funding was allocated to publishing fees as well as conference registration and travel that would have allowed us to present our findings at national and international conferences.

31. Furthermore, as an early-career scholar, the termination of this funding may put me at jeopardy of not receiving tenure or promotion to associate professor in the future. My income comes from a base salary plus incentive pay for NIH funding above and beyond what is required. Without the NIH funding, my income will be substantially reduced.

32. The decision to not remove "DEI language" from my research aims was not an easy one and has caused me a great deal of stress. Changing the language would reduce the integrity of the scientific rigor of this project, as the theoretical and conceptual underpinnings integrate minority stress, allostatic load, and intersectionality of multiple social identities. Moreover, NIH pressure to "renegotiate the scope of my award" has put me in a very difficult position: To turn my back on my morals, the research I have conducted, the participants who have trusted me with their stories, and the LGBTQ+ community with whom I have worked to build trust, or to turn my back on my co-investigators and my staff members who will lose their jobs if I refuse to renegotiate. This was not an easy decision to make, but ultimately, I cannot in good conscience erase the stories and identities of my research participants just to "align with the new NIH/HHS priorities" that were not in effect when the grant was awarded.

33. I understand that, as a class representative, I represent the interests of everyone in the class, and not just myself. I am prepared to stay informed about what is happening with my case and stay in touch with my attorneys to give them information they need. I am committed to being a class representative because I do not want other researchers to be subjected to the same unlawful policies and actions that I have experienced. I have never served as a class representative in any prior action.

I declare under penalty of perjury that the foregoing is true and correct, and that this declaration was executed at Millcreek, Utah this 8th day of September 2026.

Sara Jackson

Sara Jackson