



Dear Member of Congress,

The Coalition for Clinical Trial Equity (CCTE) congratulates you on joining the 119th Congress. The CCTE is a collaborative initiative launched by the Foundation for Sarcoidosis Research (FSR) and 26 chronic disease and/or health organizations to address disparities and access challenges in clinical trial participation. We look forward to working with you to improve the clinical trial landscape for patients who experience a lack of treatment options for their chronic and/or rare disease.

The CCTE's mission is to foster a more inclusive research landscape by dismantling barriers and increasing representation and access in clinical trials. Through collective efforts, we seek to pave the way for more equitable access to clinical trials and ultimately improve health outcomes for all patients, including communities that are traditionally underrepresented in clinical research. We urge you to join us in supporting initiatives to improve access to clinical trial participation. More specifically, please support, cosponsor, and otherwise work to pass legislation focused on enhancing clinical trials access.

We ask for your support in reforming clinical trial participation to address concerns over compensation, its complexity, and how it impacts other facets of health care by potentially, 1) officially clarifying in statute with the US Department of Labor (DOL) that the *Family & Medical Leave Act* (FMLA) already covers participation in a clinical trial and extends necessary protections – in November of 2024, the DOL issued a [letter to FSR](#) clarifying that FMLA guarantees job security for patients (and their caregivers) when they choose to participate in clinical trials 2) providing patients enrolling in clinical trials a one-time federal tax credit for up to \$5,000 for travel and related expenses associated with clinical trial participation, 3) removing taxes and other penalties, within reason and with guardrails, to further incentivize participation in clinical trials, and/or 4) providing HSA flexibility to cover clinical trial participation expenses.

Finally, we ask that you support ongoing initiatives and programs led by federal agencies such as the National Library of Medicine, the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the FDA, and NIH to improve clinical trial participation and access.

Thank you for your time and consideration of these requests. We look forward to working with you throughout the 119th Congress.

Sincerely,
The Coalition for Clinical Trial Equity

Meet Our Steering Committee:

Bioethicists

- Arthur Caplan, PhD
- Jennifer Miller, PhD
- Sonya Charles, PhD

Patients & Care Partner*

- Jessica Propps*
- Kathryn Washington, MPH
- Mary Oldham
- Purvis Hunt, MA