Dear Senators/Representatives,

The undersigned organizations, representing millions of Americans with rare and genetic diseases, advocates, industry, and academic institutions, write to express strong support for S. 139/H.R. 209, the Ensuring Access to Clinical Trials Act of 2015. This legislation will permanently remove a barrier to clinical research and allow Supplemental Security Income (SSI) and Medicaid recipients to participate in and benefit from clinical trials without fear of losing vital benefits.

The Ensuring Access to Clinical Trials Act of 2015 eliminates the sunset clause from the Improving Access to Clinical Trials Act of 2009 (IACT), legislation signed into law in 2010, making the IACT a permanent law. This will allow patients with rare diseases to continue to receive up to $2,000 in compensation for participating in clinical trials without that compensation counting towards their income eligibility limits for SSI and Medicaid.

Removing barriers to drug trial participation is particularly important as recent advances in medical research and technology allow for the development of new and promising medications. Securing an adequate number of clinical trial participants is vital for therapies that treat rare conditions, but rare disease researchers in particular often have difficulty recruiting drug trial participants, simply because they have a smaller pool of patients.

Further, with the advent of precision medicine, therapies are being customized to treat a patient’s specific genetic makeup. These types of trials often require clinical trial participants bearing specific genetic mutations, which necessarily creates an even more complex and exclusive clinical trial recruitment process. Ensuring that all patients with rare diseases are able to participate in clinical trials can help open the door for the advancement of new targeted therapies in many important areas of medicine, including cancer and rare diseases like cystic fibrosis.

Now is the time to ensure that all patients have access to clinical trials for potentially life-saving treatments. We look forward to working with you to secure passage of this bill to enable Social Security beneficiaries to participate in clinical trials so that research into life-saving treatments may to continue to advance.

Sincerely,