

## [S. 139, Ensuring Access to Clinical Trials Act of 2015](#)

### FLOOR SITUATION

On Monday, September 28, 2015, the House will consider [S. 139](#), the Ensuring Access to Clinical Trials Act of 2015, under suspension of the rules. S. 139 was introduced on January 8, 2015, by Sen. Ron Wyden (D-OR) and passed the Senate by unanimous consent on July 17, 2015.

### SUMMARY

S. 139 repeals the sunset provision in Section 3 of the Improving Access to Clinical Trials Act of 2009 (P.L. 111-255), thereby extending the exemption indefinitely, to allow payments up to \$2,000 annually to individuals for participating in clinical trials for rare diseases. Such payments would continue to not be counted as income in determining eligibility for benefits under the Supplemental Security Income and Medicaid programs. The exemption is currently set to sunset on October 5, 2015.<sup>1</sup>

### BACKGROUND

In 2009, the Improving Access to Clinical Trials Act was enacted, which among other things, shielded up to \$2,000 of individual income from being counted towards income eligibility limits for Supplemental Security Income and Medicaid benefits. According to stakeholders, “the law has helped to remove barriers for patients to participate in clinical trials—a critical issue for the rare disease community, as the majority of rare diseases still have no treatment.”<sup>2</sup>

According to the bill sponsor, “Clinical trials are an essential part of finding new treatments and cures for rare diseases, and it can often be difficult to find participants. By removing this sunset, the Senate has affirmed its commitment to seeking cures for rare diseases and removing barriers so all have the opportunity to participate in clinical trials.”<sup>3</sup>

### COST

<sup>1</sup> See CRS Report, [Health Care-Related Expiring Provisions, First Session of the 114th Congress](#), March 25, 2015.

<sup>2</sup> See National Organization for Rare Disorders Press Release, [Ensuring Access to Clinical Trials Act of 2015 Passes in the U.S. Senate](#), July 17, 2015.

<sup>3</sup> See Senate Finance Press Release, [Wyden, Hatch, Markey Applaud Senate Passage of Access to Clinical Trials Bill](#), July 16, 2015.

The Congressional Budget Office (CBO) estimates that enacting S. 139 would cost less than \$500,000 over the 2015 to 2025 period.

### **STAFF CONTACT**

For questions or further information please contact [John Huston](#) with the House Republican Policy Committee by email or at 5-0190.