Secretary Azar:

I stand with the undersigned parents, patients, health care providers, public health professionals and advocates and urge you to act immediately to renew the activities of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC). Despite the lapse in the Committee’s Congressional authorization, you have the authority to ensure the life-saving work of the ACHDNC continues.

For nearly 20 years, the ACHDNC has provided direction, guidance and evidence-based recommendations to advance newborn screening. Because of the work of the ACHDNC, states screen for more conditions and there is greater uniformity between states in the number of screened conditions and the quality of screening programs. The work of the ACHDNC has saved lives and prevented disability for thousands of infants and children.

On behalf of the 12,000 babies each year that are impacted by newborn screening, please use your authority to extend the charter of the ACHDNC allowing it to resume its essential work. With the Committee’s next meeting tentatively scheduled for February 13-14, now is the time to act.