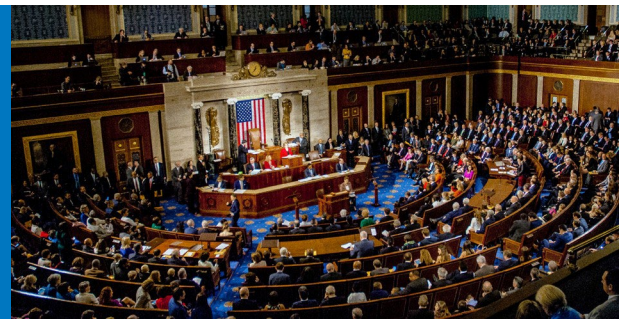


## HDSA Legislation Fact Sheet: 119th Congress



*In response to the HDSA Advocacy Priority survey, HDSA has identified priority legislation. The legislation aligns with what the community shares is most important to them to improve the lives of everyone affected by Huntington's disease and their families.*

Increase Access to Medication and Medical Devices		
LEGISLATION	DESCRIPTION	OPPORTUNITY
<b>Providing Realistic Opportunity to Equal and Comparable Treatment for RARE Act</b>	This bill allows Medicare and Medicaid to use additional sources when considering whether rare disease therapies meet the standard for "medically accepted indications" to provide coverage. It requires private payers to create an expedited review when medications or biologics have been denied.	Increases access to new therapies as they become available.
<b>HELP Copays Act (S. 864)</b>	This bill prohibits the use of copay accumulator schemes developed by health plans and pharmacy benefit managers to pocket the copay assistance a patient receives from a pharmaceutical company.	Copay assistance cannot be excluded from counting towards a patient's health plan deductible or out-of-pocket maximum.
<b>Safe Step Act</b>	This bill requires a health plan to implement and make readily available a clear process to request an exception to step therapy, including required information and criteria for granting an exception, as well as to the response timeline.	Increases timely access to the most appropriate medication in a time sensitive manner.

Increase Access to Quality Care		
LEGISLATION	DESCRIPTION	OPPORTUNITY
<b>Alleviating Barriers for Caregivers Act (S. 1227 / H.R. 2491)</b>	This bill requires SSA to review and simplify the processes, procedures, forms, and communications to family caregivers to assist individuals in establishing eligibility for, enrolling in, and maintaining and utilizing coverage and benefits under the Medicare, Medicaid, CHIP, and Social Security programs.	HD families are able to reduce some of the burden of navigating the complex processes and requirements in applying for government programs that provide access to care for their families.
<b>Telehealth Coverage Act (H.R. 2263)</b>  <b>Expanded Telehealth Access Act (H.R. 1614)</b>	Makes permanent certain telehealth flexibilities under the Medicare program.  The bill permanently allows audiologists, physical therapists, occupational therapists, speech-language pathologists, and other providers designated by CMS to provide telehealth services under Medicare.	HD patients can access more care when the burden of traveling to and from HD clinics is eliminated.  Quality care is delivered in the comfort of one's own home.



Reduce Financial Burden		
LEGISLATION	DESCRIPTION	OPPORTUNITY
<b>SSI Savings Penalty Elimination Act</b> (S. 1234 / H.R. 2540)	The bill limits the dollar amount of resources used to determine eligibility for the Supplemental Security Income (SSI) program.	Increases resource limit amount from \$2,000 to \$10,000 for individuals, and from \$3,000 to \$20,000 for married couples.
<b>Credit for Caring Act</b> (S. 925 / H.R. 2036)	The bill allows a caregiver a tax credit of up to \$5,000 for 30% of the cost of long-term care expenses that exceed \$2,000 in a taxable year. This includes expenses for providing care to a spouse or other dependent relative with long-term care needs.	Reduces financial burden on HD families.  Protects generational wealth.

Speed Innovation in the Development of New Therapies		
LEGISLATION	DESCRIPTION	OPPORTUNITY
<b>Ensuring Pathways to Innovative Cures EPIC Act</b> (S. 832 / H.R. 1492)	Under the current Medicare drug price-fixing model, small molecule drugs are eligible for selection to the “Medicare Drug Price Negotiation” program following 7 years after FDA approval and the price control then goes into effect at year 9. This act delays the timeframe for small molecules to 11 years after FDA approval to be selected for price negotiation with price control going into effect at year 13.	This bill encourages investment in small molecules.

We are grateful to our sponsors.