



LEGISLATIVE POSITIONS

Rare Bill Sheet

Patients Rising Now
700 12th St. NW 700, Suite 700
Washington, DC 20005
202-679-8223

Category	PRN's Position	Bill	Title	Summary	Sponsor	Cosponsors	Status
Access	Support	HR6996	Accelerating Access for Patients Act of 2022	To amend the Federal Food, Drug, and Cosmetic Act with respect to the accelerated approval of a product for a serious or life-threatening disease or condition, and for other purposes.	Rep. Cathy McMorris Rodgers [R-WA- 5]	0	03/09/2022 Referred to the Subcommittee on Health
Access	Support	HR5607	Justice for ALS Veterans Act of 2021	To amend title 38, United States Code, to extend increased dependency and indemnity compensation paid to surviving spouses of veterans who die from amyotrophic lateral sclerosis, regardless of how long the veterans had such disease prior to death.	Rep. Elissa Slotkin [D-MI-8]	12 B	10/19/2021 Introduced in House
Access	Support	HR1184	Helping Experts Accelerate Rare Treatments Act of 2021	To amend the Federal Food, Drug, and Cosmetic Act to improve the treatment of rare diseases and conditions, and for other purposes	Rep. Paul Tonko [D-NY-20]	8 B	02/18/2021 Introduced in House
Access	Support	HR7640	Orphan Drug Act amendment	To amend the Orphan Drug Act to reauthorize a program of grants and contracts for the development of drugs for rare diseases and conditions (commonly referred to as "orphan drugs".	Rep. Gus M. Bilirakis [R-FL-12]	1 D	05/03/2022 Referred to the House Committee on Energy and Commerce
Access	Support	S4071	Helping Experts Accelerate Rare Treatments Act of 2022	A bill to amend the Federal Food, Drug, and Cosmetic Act to improve the treatment of rare diseases and conditions, and for other purposes.	Sen. Robert P. Casey, Jr [D-PA]	1 R	04/07/2022 Referred to the Committee on Health, Education, Labor, and Pensions
Access	Support	HR6888	Helping Experts Accelerate Rare Treatments Act of 2022	To amend the Federal Food, Drug, and Cosmetic Act to improve the treatment of rare diseases and conditions, and for other purposes.	Rep. Paul Tonko [D-NY-20]	1 R	03/02/2022 Referred to the Subcommittee on Health
Access	Support	HR2623	Cameron's Law	To amend the Internal Revenue Code of 1986 to restore the amount of the orphan drug tax credit, and for other purposes	Rep. Josh Gottheimer [D-NJ-5]	2 R	04/16/2021 Introduced in House
Access	Support	HR8585	National Plan to End Parkinson's Act	To direct the Secretary of Health and Human Services to carry out a national project to prevent and cure Parkinson's, to be known as the National Parkinson's Project, and for other purposes	Rep. Paul Tonko [D-NY-20]	23 B	07/28/2022 Introduced in House
Access	Support	HR3354	CHANGE Act of 2021	To provide better care and outcomes for Americans living with Alzheimer's disease and related dementias and their caregivers while accelerating progress toward prevention strategies, disease modifying treatments, and, ultimately, a cure	Rep. Linda Sanchez [D-CA-38]	44 B	05/19/2021 Introduced in House

Category	PRN's Position	Bill	Title	Summary	Sponsor	Cosponsors	Status
Access	Support	HR7265	Cerebral Palsy Research Program Authorization Act of 2022	To amend the Public Health Service Act to authorize the Secretary of Health and Human Services to carry out a program of research related to cerebral palsy, and for other purposes.	Rep. Steve Cohen [D-TN-9]	5 B	03/30/2022 Referred to the Subcommittee on Health.
Access	Support	HR6160	Access to Rare Indications Act of 2021	To amend titles XVIII and XIX of the Social Security Act and title XXVII of the Public Health Service Act to provide for coverage of certain drugs used in the treatment or management of a rare disease or condition, and for other purposes.	Rep. Doris O. Matsui [D-CA-6]	5 B	12/08/2021 Referred to the Subcommittee on Health
Access	Support	HR253	Adult Day Center Enhancement Act	To expand and enhance existing adult day programs for younger people with neurological diseases or conditions (such as multiple sclerosis, Parkinson's disease, traumatic brain injury, or other similar diseases or conditions) to support and improve access to respite services for family caregivers who are taking care of such people, and for other purposes	Rep. Barbara Lee [D-CA-13]	0	01/11/2021 Introduced in House
Access	Support	S868/HR2050	Huntington's Disease Disability Insurance Access Act of 2021	A bill to amend title II of the Social Security Act to eliminate the five-month waiting period for disability insurance benefits under such title and waive the 24-month waiting period for Medicare eligibility for individuals with Huntington's disease	Sen. Kirsten Gillibrand [D-NY] Rep. Bill Pascrell D-NJ-9]	[13 R (S) 138 B (H)]	03/18/2021 Introduced in Senate 03/18/2021 Introduced in House
Access	Support	HR6216/S3389	Sickle Cell Disease Comprehensive Care Act	To amend title XIX of the Social Security Act to establish a demonstration project to improve outpatient clinical care for individuals with sickle cell disease.	Rep. Danny K. Davis [D-IL-7] Sen. Cory A. Booker [D-NJ]	[17 B (H) 3 B (S)]	12/10/2021 Referred to the Subcommittee on Health (H) 12/14/2021 Referred to the Committee on Finance
Transparency	Support	HR1649/S579	To make a technical correction to the ALS Disability Insurance Access Act of 2019	To make a technical correction to the ALS Disability Insurance Access Act of 2019	Rep. Seth Moulton [D-MA-6] Sen. Mike Braun [R-IN]	[2 B (H) 3 B (S)]	03/08/2021 Introduced in House 03/23/2021 Became Public Law No: 117-3 (S)
Access	Support	HR3537/S1813	Accelerating Access to Critical Therapies for ALS Act	To direct the Secretary of Health and Human Services to support research on, and expanded access to, investigational drugs for amyotrophic lateral sclerosis, and for other purposes.	Rep. Mike Quigley [D-IL-5] Sen. Christopher A. Coons [D-DE]	[331 B (H) 63 B (S)]	12/23/2021 Became Public Law No: 117-79 (H) 05/25/2021 Referred to the Committee on Health, Education, Labor, and Pensions
Access	Support	S4851	National Plan to End Parkinson's Act	A bill to direct the Secretary of Health and Human Services to carry out a national project to prevent and cure Parkinson's, to be known as the National Parkinson's Project, and for other purposes	Sen. Shelley Moore Capito [R-WV]	5 B	09/14/2022 Introduced in Senate

Category	PRN's Position	Bill	Title	Summary	Sponsor	Cosponsors	Status
Access	Monitor	HR3679	Collaborative Academic Research Efforts for Tourette Syndrome Act of 2021	To amend the Public Health Service Act to provide for the expansion, intensification, and coordination of the programs and activities of the National Institutes of Health with respect to Tourette syndrome.	Rep. Albio Sires [D-NJ-8]	2 B	06/02/2021 Referred to the Subcommittee on Health
Access	Monitor	HR5551	Improving the Health of Children Act	To amend title III of the Public Health Service Act to reauthorize the National Center on Birth Defects and Developmental Disabilities, and for other purposes	Rep. Earl "Buddy" Carter [R-GA-1]	5 B	12/08/2021 Passed/agreed to in House: On motion to suspend the rules and pass the bill, as amended Agreed to by the Yeas and Nays: (2/3 required): 405 - 20 (Roll no. 418).(text: CR H7516-7517)
Affordability	Monitor	HR3880	The Alzheimer's Research and Caregiving Trust Fund Contributions Act	To amend the Internal Revenue Code of 1986 to allow for contributions to the Alzheimer's Research and Caregiving Trust Fund, and for other purposes.	Rep. Thomas R. Suozzi [D-NY-3]	20 B	06/15/2021 Referred to the Subcommittee on Health
Access	Monitor	S350/HR482	Newborn Screening Saves Lives Reauthorization Act of 2021	A bill to amend the Public Health Service Act to reauthorize certain programs under part A of title XI of such Act relating to genetic diseases, and for other purposes	Sen. Maggie Hassan [D-NH] Rep. Lucille Roybal-Allard [D-CA-40]	[14 B (S) 57 B (H)]	02/22/2021 Introduced in Senate 06/23/2021 Passed/agreed to in House
Access	Monitor	HR8641	Orphan Drug COVID-19 Mitigation Act of 2022	To mitigate the effects of the COVID-19 pandemic on incentives under the Federal Food, Drug, and Cosmetic for the development of orphan drugs, and for other purposes	Rep. Josh Gottheimer [D-NJ-5]	2 B	08/02/2022 Introduced in House
Transparency	Monitor	HR853	Closing Loopholes for Orphan Drugs Act	To amend title III of the Public Health Service Act to limit the orphan drug exclusion under the drug discount program under section 340B of such title	Rep. Peter Welch [D-VT-AL]	1 R	02/04/2021 Introduced in House
Transparency	Monitor	HR1629	Fairness in Orphan Drug Exclusivity Act	To amend the Federal Food, Drug, and Cosmetic Act with respect to limitations on exclusive approval or licensure of orphan drugs, and for other purposes	Rep. Madeleine Dean [D-PA-4]	2 B	05/19/2021 Passed/agreed to in House: On passage Passed by the Yeas and Nays: 402 - 23 (Roll no. 150).(text: CR H2561)