



MAKING ALS LIVABLE IN New York



The ALS Association has created a state roadmap identifying eight policies that when adopted will significantly improve the health, well-being, and longevity of people living with ALS. It is the mission of The ALS Association to make ALS a livable disease until we can cure it.

Overall Award



KEY Gold Silver Bronze Future Medalist

| POLICY AREA | DESCRIPTION | MEDAL |
|---|--|-------|
| Medigap/ Medicare Supplemental | For those under 65 with a qualifying disability: Does the state require some or all Medigap plans to be offered? If so, are they affordable? | |
| Genetic Testing Protection Act Laws (GTPA) | Does the state ban price or issuance discrimination in life, long-term care, or disability insurance based on genetic testing? | |
| Fail First/Step Therapy Reform | Does the state prohibit or limit the use of “fail first” or step therapy protocols that prevent patients from accessing medications in a timely manner? | |
| Telehealth Access | Is the state a member of the Interstate Medical Licensure Compact (IMLC), which streamlines licensing processes for physicians looking to practice in multiple states? | |
| Copay Accumulator Adjustment Bans | Has the state prohibited the use of copay accumulator adjustment programs by payers and pharmacy benefit managers (PBMs)? | |
| Prior Authorization (PA) Reform | Has the state reformed prior authorization (PA) practices (i.e., standardized forms, response time, length, retrospective denial, and transparency requirements)? | |
| Medicaid Expansion | Has the state expanded Medicaid coverage under the Affordable Care Act? | |
| Rare Disease Advisory Council (RDAC) | Has the state established a Rare Disease Advisory Council and, if so, does it publicly report findings/outcomes? | |



Funding Award



New York appropriated \$300,000 for Fiscal Year 2024 for ALS Care Services. These critical dollars significantly benefit New Yorkers living with ALS. We appreciate policymakers’ support!



Extra Credit

Effective June 2023, New York will require insurers and Pharmacy Benefit Managers (PBMs) to disclose information about their cost, benefit, and coverage data. The state also honors ALS Awareness Month in May of each year.



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About the State Roadmap



The ALS Association surveyed all 50 states and the District of Columbia (DC) across eight priority policy areas that affect people living with ALS. All states and DC were evaluated on the legislation, regulations, and programs in place as of December 31, 2022. If a state or DC demonstrated notable progress in a category after December 31, 2022, this was identified in the Extra Credit section and will be noted for scoring in the next state roadmap.

Each state was awarded points based on existing policies to meet the needs of their constituents living with ALS. Each category is worth 15 points, with a total possible score of 120 points. To formulate the scores, analysts researched state policies using multiple sources including state statutes, regulations, state-issued guidance, and resources provided by medical associations and other leading health care organizations. Research citations can be found at als.org/state-roadmaps/citations. The state is awarded a medal for its overall score, which is based on the tally of the eight category scores. The overall scoring rubric is below, and more information about the scoring of each policy area can be found at als.org/state-roadmaps.

Recognizing that many state legislatures are still becoming familiar with The ALS Association’s policy priorities, we view this roadmap as a learning tool to educate policymakers about how they can make ALS more livable in their state.

Overall Scoring Rubric

-  **Gold:** 100-120 points
-  **Silver:** 70-99 points
-  **Bronze:** 40-69 points
-  **Future Medalist:** 0-39 points

About The ALS Association



We are the world’s leading ALS organization, made up of volunteers who are living with ALS, loved ones, caregivers, advocates, and dedicated staff. In 2022, our care services teams in communities throughout the country served more than 21,000 people living with ALS, including more than 2,000 veterans. We fight ALS on every front by leading the way in global research, providing comprehensive care services, coordinating multidisciplinary care through certified clinical care centers, and advancing public policy. **Our goal is to make ALS livable for everyone, everywhere, until we can cure it.**

Glossary

Medigap: Health insurance sold by private insurance companies to fill the “gaps” in traditional Medicare, also known as ‘Medicare supplemental’ plans.

Genetic Protection Testing Act (GTPA):

Legislation to prohibit insurers from discriminating in pricing and issuance of life, long-term care, and disability insurance.

Fail First/Step Therapy: A cost-control mechanism used by insurance companies that requires patients to try and “fail” on one or more medications approved by the insurer before being allowed to “step up” to the actual medication prescribed for them.

Telehealth: Virtual health care services provided to patients via telecommunication technologies, including both video and audio-only.

Copay Accumulator Adjustment Policies: A tactic used by health insurers to prohibit coupons or “copay assistance programs” from counting toward the patient’s annual deductible or the maximum out-of-pocket costs, resulting in patients having to pay up to their out-of-pocket maximums to obtain medications.

Prior Authorization: A cost-control mechanism where advanced approval from a health plan is required for care. Also known as “precertification” or “prior approval.”

Medicaid Expansion: A provision of the Affordable Care Act (ACA) that gives states the option to expand Medicaid coverage to adults with incomes up to 138% of the Federal Poverty Level.

Rare Disease Advisory Council (RDAC): An advisory body that gives the rare disease community a stronger voice in state government.