

February 23, 2026

Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Re: Guarding U.S. Medicare Against Rising Drug Costs (GUARD) Model (CMS-5546-P)

Dear Administrator Oz:

The undersigned organizations – representing patients, people with disabilities, caregivers, older Americans, providers, veterans, and others – are writing to urge the immediate, full withdrawal of the Guarding U.S. Medicare Against Rising Drug Costs (GUARD) Model. Five years ago, many of the undersigned organizations also submitted similar comments voicing our strong opposition to similar proposed demonstrations. Since then, the track record of problems and harms from health policy decisions grounded in cost-effectiveness thresholds devaluing lives lived with disabilities and older adults has grown even longer.

We are deeply disturbed that the Administration again seeks to model other countries that are so far behind the United States in access to drugs for serious and disabling conditions. We support the agency's goal of lowering drug prices for all Americans, but it is critical that it is done in ways that work for all Americans. Policy that references discriminatory cost-effectiveness standards like the quality-adjusted life year (QALY) used by many other countries is the wrong approach. The statute creating the Center for Medicare and Medicaid Innovation (CMMI) was intended to center its work on patients and people with disabilities, valuing their lives and their lived experiences. We are concerned that the GUARD model moves in the opposite direction, and would instead import standards for policymaking used in Organisation for Economic Co-operation and Development (OECD) countries that devalue many patients and people with disabilities, ignore differences in the needs of individual patients and their families, and lead Americans to experience similar delays in access to innovation. We are concerned that this rule proposes to:

- Rely on cost-effectiveness assessment and the discriminatory QALY, which violates current statute that includes safeguards against the use of the QALY and similar metrics in Medicare.
- Lead to a health system devaluing disability that is in direct conflict with American civil rights and disability policy by importing policies that rely on the premise that people with disabilities and older adults are less valuable and less worth treating than “healthy” people.

- Reduce beneficiary access to certain Part D drugs, including those covered by the model or other drugs that may be subjected to adverse utilization management as an unintended consequence.
- Make America more like the referenced countries where individual lives are assigned a numeric value, where treatments for people with disabilities and older adults have lower value, and patients are forced to wait at length for their approval and access to them.
- Reference countries in which cost-effectiveness standards and health technology assessment processes routinely deprioritize patients with serious diseases and conditions by imposing long decision-making delays and ignoring outcomes that matter to patients such as improved quality of life and reduced burden on family caregivers.

We urge CMMI to put in place safeguards to ensure that patients and people with disabilities are at the center of decision-making. We encourage the administration to work with our communities to develop patient-centered alternatives that recognize the inherent value of every person.

CMS Must Reject Use of QALY-based Cost-Effectiveness Standards and Honor the Safeguards Against Their Misuse in Medicare

The United States has a thirty-year-long, bipartisan track record of opposing the use of the QALY and other metrics devaluing people with disabilities by putting appropriate safeguards in place to mitigate their use. We are concerned that the GUARD Model violates these protections.

Under the new GUARD model, Medicare would import the values and standards of referenced countries – including countries that employ QALYs – by importing the drug prices set using those standards. The proposal would call for rebates that, in effect, set U.S. drug prices at rates set using metrics of cost effectiveness known to devalue people with disabilities, older adults and other vulnerable patient groups. The proposed model would run for seven years, be mandatory for manufacturers of GUARD-eligible drugs, and apply to a geographically selected Part D beneficiary cohort representing approximately 25 percent of beneficiaries. Comparators include countries like the United Kingdom, Canada, Australia, and the Netherlands. A new analysis by the Office of Health Economics (OHE) – the world’s oldest independent health economics research organization – sheds light on this crucial issue, showing that 18 of 19 countries listed in the GUARD model reference QALYs.¹ QALY-based assessments assign a financial value to health improvements and outcomes. When applied to health care decision-

¹ <https://www.pipcpatients.org/news/the-data-mine-new-analysis-by-highlights-why-the-us-could-back-into-use-of-qalys-by-referencing-other-countries>

making, the results can mean that some patients – particularly those with disabilities and chronic illnesses, and seniors – are worth less to treat.

We are concerned that, in adopting this model, CMS would undermine key protections intended to equally value all lives, including those of people with disabilities and serious chronic conditions. Other experts agree with this assessment, across the political spectrum.² In a report, the National Council on Disability (NCD), an independent federal agency, made the recommendation that “CMS should refrain from pursuing means of reducing Medicare and Medicaid prescription drug costs that attempt to model US pricing after the pricing in other countries, which may heavily rely on QALYs and often deny people with disabilities access to needed care.” NCD’s rationale for this argument is that consideration of the QALY in public programs would be contrary to United States civil rights and disability policy.³

The Affordable Care Act (ACA) directly states that the Secretary of Health and Human Services has no authority to deny coverage of items or services “solely on the basis of comparative effectiveness research” nor to use such research “in a manner that treats extending the life of an elderly, disabled, or terminally ill individual as of lower value than extending the life of an individual who is younger, nondisabled, or not terminally ill.”⁴ Additionally, legislation specifically prohibits the development or use of a “dollars-per-quality adjusted life year (or similar measure that discounts the value of a life because of an individual’s disability) as a threshold to establish what type of health care is cost effective or recommended.” The ACA also states, “The Secretary shall not utilize such an adjusted life year (or such a similar measure) as a threshold to determine coverage, reimbursement, or incentive programs under title XVIII (Medicare).”⁵ The GUARD model appears to directly violate these critical and intentionally crafted safeguards.

The opposition to the QALY far pre-dates the ACA. Section 504 of the Rehabilitation Act ensures that people with disabilities will not be “excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination,” under any program offered by any Executive Agency, including Medicare.⁶ Title II of the Americans with Disabilities Act (ADA) extended this protection to programs and services offered by state and local governments.⁷ Based on this, in 1992, the George H.W. Bush Administration established that it would be a violation of the ADA

² <https://valueourhealth.org/wp-content/uploads/2020/04/IPI-One-Pager.pdf>

³ National Council on Disability. (November 16, 2019). Quality-Adjusted Life Years and the Devaluation of Life with Disability. https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf.

⁴ 42 USC Sec 1320e, 2017.

⁵ 42 USC Sec 1320e.

⁶ 29 USC Sec 794.

⁷ 42 USC Sec 12131.

for state Medicaid programs to rely on cost-effectiveness standards, as this could lead to discrimination against people with disabilities.⁸

The GUARD model violates these safeguards, as well as clear precedent, by basing rebate decisions on countries that rely on QALY-based cost-effectiveness analyses.

Beneficiary Access Challenges Could Extend Even Beyond Part D and to Drugs Not Covered Under the New Model

CMS acknowledges that the GUARD Model does not directly impact Part D patient out-of-pocket costs for selected drugs and highlights scenarios where patients may – or may not – benefit. It is especially concerning that CMS openly predicts that cost-sharing and premiums are likely to rise, increasing patient costs in Part D by \$3.6 billion.⁹ As we understand, cost sharing would be reduced for patients only if a manufacturer drops their list price or a plan changes their cost-sharing structure. The more likely scenario implicitly acknowledged by CMS' predictions are the ample opportunities for patients to be subjected to unintended consequences of the model: increased cost sharing for the selected drug or others in its class, increased use of utilization management strategies that undermine access to the drug that patients and providers agree to be the most effective option, undermined access to the six protected classes, or even impacts beyond Medicare. A model centered on patients and people with disabilities would be safeguarded against such negative consequences.

CMS did not discuss the potential implications for utilization management as pressure on payers may lead to formulary changes, particularly increased prior authorization and step therapy that undermine clinical care and decision-making. These unintended – but predictable – consequences are reminiscent of the challenges experienced by patients in the same foreign countries referenced by these models, where patients and physicians have little choice in treatment decisions, reflecting a culture that does not value older adults and people living with disabling conditions. Instead, in America, we would expect policy to be focused on strategies that drive personalized care choices that allow for access to the most clinically effective treatment.

Finally, this new Part D rebate mechanism could have implications for drug pricing that go beyond Part D. The impact on list prices will influence the formularies and utilization management strategies of commercial and private plans. While CMS proposes a standard monitoring and compliance framework, the reality is that CMMI will not be positioned to address many of the challenges that emerge, particularly outside the Medicare program.

⁸ Sullivan, Louis. (September 1, 1992). Oregon Health Plan is Unfair to the Disabled. The New York Times. <https://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html>

⁹ CMS-5546-P, TABLE C5: IMPACTS TO MEDICARE PART D ENROLLEES (\$ BILLIONS) <https://public-inspection.federalregister.gov/2025-23705.pdf#page=217>

Importing QALY-Based Cost-Effectiveness Thresholds Will Make America Like Other Countries That Do Not Prioritize Access to Innovative and Needed Treatments

The implications of devaluing people with disabilities and chronic illnesses plays out clearly in comparator countries that rely on cost-effectiveness analyses to determine coverage and reimbursement of prescription drugs. The recent draft Health Technology Assessment (HTA) methods report released by the Health Economics Methods Advisory (HEMA) group makes it crystal clear – policy grounded in conventional HTA methods (like the QALY) are willing to harm the individual for the sake of the formula-derived average. When pricing reflects what *patients* value, innovators naturally focus on developing treatments that meet those needs. HEMA’s framework – similar to countries like the United Kingdom that rely on QALY-based decision-making – breaks that link by anchoring valuation to population averages and HTA-defined metrics, signaling to developers that serving the model matters more than serving the patient. When countries reward alignment with HTA metrics instead of patient priorities, progress to address unmet patient needs is slowed, especially for communities often overlooked in trial averages, such as people with rare diseases, disabilities, or rapidly progressing conditions.¹⁰ By contrast, America has laws to prevent reliance on HTA metrics like QALYs, instead organizing and financing health care in ways that prioritize choice and individualized decision-making, benefiting American patients as innovations are approved and available to patients here first.

For example, the National Institute of Health and Care Excellence (NICE) conducts cost-effectiveness analyses to determine what treatments and drugs will be covered by Britain and Wales’ National Health System (NHS). NICE’s reports are known to restrict patients’ access to care, particularly among individuals with complex conditions.¹¹ In countries like the United Kingdom, treatments for older patients – that make up a significant portion of cancer patients – face greater challenges getting covered.¹² In 2024, we noted reports of a substantial rise in terminated NICE appraisals, from 16.6% in 2017 to 25.6% in 2022, disproportionately impacting products with multiple indications (typically for cancer patients), making up 63.9% of terminations. As reported, companies were increasingly choosing not to submit to NICE on the basis that demonstrating cost-effectiveness at the current price would be too difficult.¹³ Another report showed that in 2024 only 56% of approved medicines were available to English patients, down from 66% in 2023. Half of those faced restrictions beyond the labeled

¹⁰ USC Schaeffer Responses to HEMA: Why Patients Shouldn’t Bear Individual Harms for Better Population Averages, December, 2025 <https://www.pipcpatients.org/news/usc-schaeffer-responses-to-hema-why-patients-shouldnt-bear-individual-harms-for-better-population-averages>

¹¹ Sarah Long, “Squashed Dreams and Rare Breeds: Ableism and the Arbiters of Life and Death,” *Disability and Society* 30 (2015): 1118–22.

¹² https://www.fortrea.com/sites/default/files/2025-03/nice-technology-appraisals-of-oncology-treatments_1.pdf

¹³ <https://www.medrxiv.org/content/10.1101/2024.08.06.24311489v1.full.pdf>

indication.¹⁴ Not surprising, the U.K. ranks among worst in the world for cancer survival.¹⁵ It tells a disheartening story about patients having to leave the country to access care, or being denied access to care altogether.^{16,17}

The same pattern exists across countries that rely on similar assessments to determine coverage and reimbursement. Only about half of approved rare disease drugs are available in Denmark, and half of those face restrictions, even after taking over a year to be made available to patients.¹⁸ It takes over 2 years from the time of approval in the United States for a drug to be available in Australia.¹⁹ Canadians wait around 2.5 years after their approval process is complete for meaningful availability and public coverage of certain blood cancer treatments.²⁰ Even when medicines are available, there are frequently significant restrictions placed on medicine use that further limits access even after they have been prescribed by a physician. One Canadian family shared that a drug for Wilson Disease took 36 years from the time it was available in the U.S. to be available in Canada, and that too many patients are forced to fail on old therapies and to go through long appeals before getting access to the newer therapies available in the U.S.²¹ These restrictions lead to harmful delays in access to care for patients, and in some instances, patients may be required to get “sicker” before qualifying to access treatment, leading to irredeemable losses to their health.²²

As cited by the NCD in their report on QALYs,²³ these access restrictions and delays have the effect of worse health outcomes for people in countries that rely on cost-effectiveness assessments. Survival rates for some types of cancer, like lung cancer, are higher in the U.S. than abroad.²⁴ One study looking at non-small cell lung cancer found that if the actual access conditions in the U.S. between 2006 and 2017 were replaced with access conditions in five ex-U.S. comparator countries, the aggregate survival gains for U.S. patients would have been cut in

¹⁴ <https://www.abpi.org.uk/media/blogs/2024/june/comparing-new-medicine-availability-across-europe/>

¹⁵ <https://ecancer.org/en/news/24058-uk-survival-ranksamong-the-worst-in-the-world-for-deadliest-cancers>

¹⁶ <https://www.the-independent.com/life-style/health-and-families/rare-cancer-signs-rhabdomyosarcoma-gofundme-b2792476.html>

¹⁷ https://www.pipcpatients.org/uploads/1/2/9/0/12902828/pipc_uk.pdf

¹⁸ <https://www.efpia.eu/media/oeganukm/efpia-patients-wait-indicator-2024-final-110425.pdf>

¹⁹ Lingaratnam S, Hussainy SY, Murphy A, Perrin C, Samuvel M, Mehrvarz E, Lim CX, Zalberg J. Australian access to FDA-approved breakthrough therapy designation medicines: a 10-year review. *J Pharm Policy Pract.* 2024 Aug 21;17(1):2389120. doi: 10.1080/20523211.2024.2389120. PMID: 39175661; PMCID: PMC11340226.

²⁰ <https://www.saltwire.com/nova-scotia/no-time-to-wait-canada-fails-to-provide-modern-treatment-options-for-blood-cancer-patients3>

²¹ <https://www.youtube.com/watch?v=1MwieBU66uA>

²² <https://youtu.be/OZsYeSfjPnE>

²³ National Council on Disability. (November 16, 2019). Quality-Adjusted Life Years and the Devaluation of Life with Disability. https://www.ncd.gov/assets/uploads/reports/2019/ncd_quality_adjusted_life_report_508.pdf

²⁴ Ziba Kashaf, “Disparities Found in Lung Cancer Care, Survival in U.S. Versus England,” *YaleNews* (blog), May 1, 2018, <https://news.yale.edu/2018/05/01/disparities-found-lung-cancer-care-survival-us-versus-england>

half.²⁵ Therefore, NCD has recommended policymakers abandon international referencing pricing policies, stating “there has been increasing interest by the Federal Government in reducing the cost of health care by modeling parts of its national health insurance programs after the healthcare systems of other countries, such as the United Kingdom. Several of these countries utilize QALYs to make benefits and coverage decisions. The coverage denials and loss of access to care faced by people with disabilities in these countries illustrate what might happen if the United States made a similar choice.”²⁶

Importing Foreign Pricing Models Has Concerning Moral and Ethical Implications

There is widespread opposition to QALY-based cost-effectiveness thresholds being used in health care decision making because of its many ethical and methodological flaws.^{27,28} The QALY methodology uses numeric “utilities” to quantify the value of different health states. The utility assigned to a given hypothetical state of health is based upon the preferences of the general public as measured by large, country-specific surveys. The highest possible utility for a health state is 1, representing perfect health. Zero represents death. Thus, the QALY assumes that time spent in some states is more desirable than others. For example, paraplegia is identified by some QALY systems at approximately 0.5, implying that the lives of people with paraplegia are worth approximately half the lives of individuals without.²⁹ Some QALY systems have even gone so far to assign health states, like severe ALS, negative utilities, implying there are health states worse than death.³⁰

When QALYs are applied to assessing the value of a treatment, they will inherently find that treatments designed to treat younger, healthier populations have “higher value” and will undervalue treatments designed to treat older, chronically ill, and disabled populations. Consequently, the QALY will then find “less value” in treatments that maintain the current quality-of-life or provide incremental improvements over treatments that bring patients closer to optimal health. This means that treatments that provide incremental quality of life

²⁵ Wayne Su, “Comparing Health Outcome Differences Due to Drug Access: A Model in Non-Small Cell Lung Cancer,” IHS Markit, December 13, 2018,

https://cdn.ihs.com/www/prot/pdf/0119/IHSM_NSCLC%20HTA%20model%20white%20paper_18Jan2019r.pdf.

²⁶ National Council on Disability. (November 16, 2019). Quality-Adjusted Life Years and the Devaluation of Life with Disability. https://www.ncd.gov/assets/uploads/reports/2019/ncd_quality_adjusted_life_report_508.pdf

²⁷ Knapp M, Mangalore R: “The trouble with QALYs...”. *Epidemiologia e psichiatria sociale* 2007, 16(4):289-293.

²⁸ Brazier JE, Rowen D, Lloyd A, Karimi M. Future directions in valuing benefits for estimating QALYs: is time up for the EQ-5D?. *Value in Health*. 2019 Jan 1;22(1):62-8.

²⁹ Haagsma JA, Polinder S, Cassini A, Colzani E, Havelaar AH. Review of disability weight studies: comparison of methodological choices and values. *Popul Health Metr*. 2014;12:20. Published 2014 Aug 23. doi:10.1186/s12963-014-0020-2

³⁰ Ackerman, S.J., Sullivan, E.M., Beusterien, K.M. et al. Cost Effectiveness of Recombinant Human Insulin-Like Growth Factor I Therapy in Patients with ALS. *Pharmacoeconomics* 15, 179–195 (1999).

<https://doi.org/10.2165/00019053-199915020-00006>

improvements for chronic illnesses or disabilities are likely deemed low value, despite that incremental improvements are of great value to the indicated populations.

This type of methodology entirely ignores the fact that a person living with a disability or chronic illness may view their lives as having value and being worthy of treatment to extend life or improve quality of life.³¹ Valuing individuals with “perfect” health more than those who are disabled or chronically ill is mired with ethical issues. In some countries that rely on QALYs to make health decisions, people may be covered to receive the drugs to die through assisted suicide but not the treatment to live.^{32,33,34} While the United States has strict laws protecting access to care for people with disabilities, other countries openly ration care in ways that disadvantage older adults and people with disabilities.³⁵ Their disability discrimination laws fall short of those here in the United States where health systems are by law required not to deny care based on perceptions of a person’s worthiness of treatment or views that their quality of life is not worth living.³⁶

Tying health care decisions to measures that devalue disability and advanced age is counterintuitive to American values. Our public policies should advance the goal of equal access to care for all Americans. A prime example of this is the Emergency Medical Treatment and Labor Act (EMTALA), a federal law that requires anyone coming to an emergency department to be stabilized and treated regardless of their ability to pay.³⁷ The COVID-19 pandemic also opened the nation’s eyes to the implications of a health care system devaluing disability, instigating the first Trump administration to respond to the pandemic with public policies protecting people with disabilities from being denied access to health care.³⁸ Even infants with disabilities are at risk if the United States decide to embrace the standards of other countries that devalue disabled lives.³⁹

³¹ Pettitt, D., Raza, S., Naughton, B., Roscoe, A., Ramakrishnan, A., Davies, B., . . . Brindley, D. (2016). The Limitations of QALY: A Literature Review. *The Journal of Stem Cell Research & Therapy*, 6(4).

³² Jamil, U., & Pearce, J. M. (2025). Government Economics of Expanding Canada’s Medical Assistance in Dying to Vulnerable Populations and the Ethical Implications of Allowing the State to Control Death. *OMEGA - Journal of Death and Dying*, 0(0). <https://doi.org/10.1177/00302228251323299>

³³ <https://www.alliancevita.org/en/2023/09/belgium-is-euthanasia-economical/>

³⁴ <https://www.rtl.be/actu/christophe-pere-de-4-enfants-besoin-dun-medicament-tres-cher-pour-survivre-le/2019-07-11/article/226336>

³⁵ <https://www.forbes.com/sites/sallypipes/2024/05/28/dont-import-british-methods-for-rationing-access-to-drugs/>

³⁶ 45 CFR Part 84 at 54.86 and 54.87

³⁷ Centers for Medicare & Medicaid Services. (2012, March 26). Emergency Medical Treatment & Labor Act (EMTALA). <https://www.cms.gov/regulations-and-guidance/legislation/emtala/>

³⁸ U.S. Civil Rights Office Rejects Rationing Medical Care Based on Disability, Age, *New York Times*, 2020 <https://www.nytimes.com/2020/03/28/us/coronavirus-disabilities-rationing-ventilators-triage.html>

³⁹ <https://www.ncd.gov/2015/04/23/ncd-response-to-controversial-peter-singer-interview-advocating-the-killing-of-disabled-infants-professor-do-your-homework/>

Studies have acknowledged that the QALY is not fit for purpose, highlighting that a health measurement tool must, above all else, measure health accurately, which the QALY fails to do.⁴⁰ Relying on such a measure to price and reimburse health care is not only inaccurate but dangerous. Importing QALY-based pricing from abroad risks deepening and entrenching health disparities faced by people with significant health needs, which is counterintuitive to our moral and ethical obligation to value all lives.

CMMI’s “Demonstration” is a Mandatory Policy Change that Imports Discriminatory Measures on a National Scale into the United States Health Care System

It is essential that cost savings do not come at the expense of the populations Medicare is designed to serve: people with disabilities, patients, and seniors. CMS proposes to implement the GUARD model as a “demonstration” under the statute that created CMMI, yet has made it mandatory for participation in the chosen zip codes. We are concerned that people subject to the demonstration who experience costly unintended consequences will not have the opportunity to quit the demonstration. In certain zip codes where health care is already scarce, including rural areas, the implications for patients could be more significant than others.

CMMI Needs to Institute Safeguards that Ensure Patients and People with Disabilities are at the Center of Decision Making

The first Trump administration published a “New Direction for CMMI” in 2017, which highlighted a “new focus on patient-centered care.” Yet, following its publication, CMMI has sought to use its authorities to import foreign system health standards, i.e. QALY-based pricing, that enable and entrench health care rationing. From our perspective, this reflects a misuse of CMMI authorities in ways that stray far from the agency’s statutory authority. Doing so will serve to erode public trust in public health agencies. We would encourage CMMI to focus its new models on demonstrations that improve outcomes that matter to patients and people with disabilities, bolstering the credibility of CMMI by making it accountable to patients. A strong first step would be to withdraw the GUARD model. This administration also has an opportunity to do what previous administrations have failed to do by establishing the “patient-centeredness criteria” mandated under Section 1115A of the Affordable Care Act, against which the statute calls for alternative payment models to be evaluated, as well as to establish meaningful safeguards around CMMI demonstration models to ensure alignment with statute and Congressional intent. Engaged patients and people with disabilities stand ready to partner with

⁴⁰ Browne J PhD, Cryer DR JD, Stevens W PhD. Is the QALY Fit for Purpose? [Internet]. AJMC; 2021 Jul 13; Available from: <https://www.ajmc.com/view/is-the-qaly-fit-for-purpose->

CMMI and Congress to focus CMMI priorities on prevention, improved health outcomes and quality of life, and informed decision-making.⁴¹

In addition to these patient-centered safeguards, new proposals should not seek to waive protections against cost-effectiveness standards currently in statute. We encourage the administration to explicitly state its intent to abide by all current legal protections against the use of QALYs and similar measures in Medicare coverage and reimbursement decisions.

Conclusion

The GUARD model is not in the best interest of America and the older adults, patients, and people with disabilities who benefit from America’s commitment to approving and covering innovations first. For these populations, access to the care they need in a timely manner is critical and directly translates into longer and higher quality lives. The GUARD model would jeopardize access to innovations optimizing health outcomes. Therefore, we urge the administration to abide by current statute, which forbids the use of QALY and similar measures in Medicare decisions, and to work directly with patients and people with disabilities.

Thank you for your consideration. Your response may be directed to Thayer Roberts, thayer@pipcpatients.org.

Sincerely,

Ability Resources, Inc.
 Access Center for Independent Living
 Access to Independence, Inc.
 Access Ready, Inc.
 ADA Watch/Coalition for Disability Rights & Justice
 Akari Foundation
 Allfocus Technologies, Inc
 Alliance for Aging Research
 Alliance for Patient Access
 ALS Association
 Alstrom Syndrome International
 American Association of People with Disabilities
 American Association on Health and Disability
 American Society on Aging

Arizona Statewide Independent Living Council
 Association of Programs for Rural Independent Living (APRIL)
 Association on Aging in New York
 Autistic People of Color Fund
 Autistic Self Advocacy Network
 Autoinflammatory Alliance
 Avery's Hope
 Biomarker Collaborative
 Blue Ridge Independent Living Center
 Bubba's Light, Inc.
 California Lupus Foundation
 CancerCare
 Caregiver Action Network
 Caring Ambassadors Program
 Center for Autism and Related Disorders

⁴¹ Partnership to Improve Patient Care, “PIPC Submits Joint Letter to CMMI Emphasizing Patient-Centered Payment Models,” Letter, August 2, 2018.
http://www.pipcpatients.org/uploads/1/2/9/0/12902828/pipc_et_al_cmmi_letter.pdf



Chronic Care Policy Alliance
Coalition of State Rheumatology Organizations
Coalition of Texans with Disabilities
Color of Gastrointestinal Illnesses
Community Access National Network
Community Resources for Independence, Inc.
CureLGMD2i Foundation
Cystic Fibrosis Research Institute
Depression and Bipolar Support Alliance (DBSA)
Diabetes Leadership Council
Diabetes Patient Advocacy Coalition
Direct Advocacy & Resource Center
Disabilities Resource Center of Siouxland
Disability Rights Education and Defense Fund (DREDF)
Eastern Shore Center for Independent Living
Endeppence Center
Endeppence Center of Northern Virginia
Epilepsy Alliance America
Epilepsy Foundation of America
Exceptional Child Center DBA CIL
Exon 20 Group
Free ME from Lung Cancer
Gem State Developmental Center
Genetic Alliance
Global Colon Cancer Association
Global Liver Institute
GO2 for Lung Cancer
Health Hats
HIV+Hepatitis Policy Institute
Huntington's Disease Society of America
Hydrocephalus Association
Hypertrophic Cardiomyopathy Association
ICAN, International Cancer Advocacy Network
Idaho State Independent Living Council
Independence Associates, Inc.
Independence Northwest, Inc.
indiGO
Infusion Access Foundation
Intermountain Fair Housing Council, Inc.
JLS Consulting
Lakeshore Foundation
LiveLung
Living Hope Wheelchair Association
Lupus and Allied Diseases Association, Inc.
Lupus Colorado
MET Crusaders
MLD Foundation
Monica Weldon Consulting, LLC
Multiple Sclerosis Foundation
National Association of Nutrition and Aging
Services Programs
National Council on Independent Living
National Fabry Disease Foundation
National Health Council
National Infusion Center Association
National Mental Health Consumers' Self-Help
Clearinghouse
NCBA, Inc.
Nevada Chronic Care Collaborative
Northern Regional Center for Independent
Living
Not Dead Yet
Partnership to Fight Chronic Disease
Partnership to Improve Patient Care
Patients' Rights Action Fund
PDL1 Amplifieds
PILC
Placer Independent Resource Services
PXE International
RetireSafe
Rosie Bartel
San Juan Center for Independence
Seniors Speak Out
Service Center for Independent Life (SCIL)
The Bonnell Foundation: Living with cystic
fibrosis
The Coelho Center for Disability Law, Policy, and
Innovation
The disAbility Resource Center of the
Rappahannock Area, Inc.
The Global Foundation for Peroxisomal
Disorders
The Hepatitis C Mentor and Support Group- H
The Kotick Network
The Libbi Thomas Foundation
The National Organization of Nurses with
Disabilities
The Ros1ders
The Speak Foundation

The Statewide Independent Living Council of
Illinois
The White Ribbon Project
United Spinal Association
Upstage Lung Cancer
US Hereditary Angioedema Association

Valley Association for Independent Living
WeMatter disability organization
Whistleblowers of America
Wisconsin Coalition of Independent Living
Centers