

PARKINSON'S POLICY FORUM

March 19–21, 2018 · Washington, DC

GLOSSARY OF POLICY TERMS

Act: Legislation that has passed both chambers of Congress in identical form and been signed into law by the president. This term also can refer to a bill that has been passed by one chamber of Congress (the House or the Senate) and will be sent to the other chamber for a vote.

Appropriation: Legislation that provides funds for an authorized agency, program or activity. The formal federal spending process consists of two steps: authorization and then appropriation.

Authorization: Legislation to create or continue an agency, program or activity. The formal federal spending process consists of two steps: authorization and then appropriation.

Bill: A legislative proposal before Congress. A bill is labeled “H.R.” if it originates in the House and “S” if it originates in the Senate.

Budget Resolution: A document passed by both chambers of Congress that sets overall spending limits but does not decide funding for specific programs. It does not have the force of law; it acts as a blueprint for the appropriations process.

Cannon, Rayburn and Longworth Buildings: House office buildings located to the south of the Capitol.

Caucus: An informal organization of members from the House and Senate (or both) with the purpose of focusing on an issue of mutual concern.

CBO: The Congressional Budget Office, a nonpartisan arm of Congress that provides economic analyses of legislation and programs covered by the federal budget.

CDC: The Centers for Disease Control and Prevention, a federal agency that conducts and supports health promotion, prevention and preparedness activities with the goal of improving overall public health.

CDMRP: The Congressionally Directed Medical Research Programs, housed in the Department of Defense. They fund disease-specific research aimed to prevent, control or cure disease. The Parkinson's Research Program (PRP) is part of the CDMRP.

Chairman and Ranking Member: The leaders of the majority and minority party, respectively, in committees and subcommittees.

Continuing Resolution: Legislation that permits federal agencies to continue operating at existing funding levels if an omnibus bill has not been adopted by the start of the fiscal year (October 1).

Dirksen, Russell and Hart Buildings: Senate office buildings located to the north of the Capitol.

Discretionary Spending: Also known as appropriated spending; must be renewed each year in order for programs to continue operating. Includes medical research, health care programs, defense and education, among others.

Donut Hole: A prescription drug coverage gap under Medicare Part D. Once beneficiaries and Medicare have spent a certain amount of money for covered prescription drugs, individuals are responsible for all out-of-pocket drug costs, up to a certain point.

FDA: The Food and Drug Administration, a federal agency within the U.S. Department of Health and Human Services. The FDA protects and promotes health through the approval and regulation of medications, medical devices and other therapies.

Filibuster: A process only in the Senate that allows senators to stall movement on legislation or nominations.

FY: Fiscal year, the accounting period for the federal government, which runs October 1 through September 30.

LD, LA, LC: Legislative Director, Legislative Assistant and Legislative Correspondent; staff positions in congressional offices in descending order of seniority.

Mandatory Spending: This type of spending pays for programs established by law that Congress is required to fund each year. It includes Social Security and Medicare, which are classified as “entitlement” programs because people meeting relevant eligibility requirements are legally entitled to them. Mandatory spending is not part of the annual appropriations process.

Medicaid: A health care program that assists low-income families or individuals in paying for long-term medical and custodial care costs. Medicaid is funded primarily by the federal government and run at the state level, where coverage may vary depending on per capita income and other criteria.

Medicare: The federal health insurance program for people 65 and older, certain younger people with disabilities and people with end-stage kidney disease.

- **Part A** (federal) covers inpatient hospital stays; skilled nursing facility stays; part of home health services and hospice care.
- **Part B** (federal) covers physician visits and lab services; allied services; preventive services; durable medical equipment; drugs administered by providers.
- **Part D** (commercial) covers both brand-name and generic prescription drugs.
- **Medicare Advantage** (sometimes referred to as Medicare Part C) is a program through which individuals can enroll in a private health plan and receive all Medicare Part A/B-covered benefits.
- **Medicare supplement** (Medigap) is insurance sold by private companies that can help pay for health care costs not covered by Medicare Part A/B.

NIH: The National Institutes of Health, the principal federal agency for health research in the United States. The NIH is part of the U.S. Department of Health and Human Services.

NINDS: The National Institute of Neurological Disorders and Stroke, one of the institutes within NIH. Its mission is to support and conduct research on the structure and function of the nervous system, as well as the causes, prevention, diagnosis and treatment of more than 600 nervous system disorders, including Parkinson's.

Omnibus Bill: Combined package of appropriation bills that leadership in both chambers negotiate in order to pass a comprehensive budget.

President's Budget: The document sent to Congress by the president each year, estimating government revenue and expenditures for the coming fiscal year. While the proposal makes budget recommendations, it does not automatically become law. It is the job of Congress to create the final budget each year.

Veto: The power of the president to block legislation passed by Congress. A veto can be overridden with a two-thirds majority vote in both houses of Congress.

GLOSSARY OF RESEARCH TERMS

Alpha-synuclein: A normal protein that clumps in the brains of people with Parkinson's disease (PD). Alpha-synuclein is the main component of Lewy bodies, which are thought to contribute to damage or death of dopamine-producing brain cells. This protein is the target of much ongoing PD research and therapeutic development.

Biomarkers: Measurable characteristics that can be used to determine the risk, presence or progression of disease. (Cholesterol is a biomarker of potential heart disease.) No biomarker of Parkinson's disease has yet been validated, but researchers are working toward such a tool.

Clinical Studies: These studies involve human volunteers. They assess the safety and efficacy of new ways to diagnose, prevent or treat disease; they also provide insight into the disease process. Clinical studies are a vital part of scientific research and are essential to developing better treatments for people with Parkinson's.

- **Observational clinical studies** do not test new treatments. Researchers observe participants' health over a period of time to learn more about the process of disease.
- **Interventional clinical trials** test the safety and efficacy of an experimental treatment, such as a new drug, an exercise regimen or a surgical procedure.

Disease-modifying Therapy: Prevents, slows, stops or reverses disease progression. Currently, there is no disease-modifying therapy for Parkinson's, but research is focused on understanding the causes of PD in order to modify proteins and biological pathways that may play a role.

Dopamine: Neurotransmitter chemical produced in the brain that helps control movement, balance and walking. Lack of dopamine is the primary cause of Parkinson's motor symptoms.

GBA1: Mutations in the GBA1 gene are the most common genetic risk factor associated with Parkinson's. The GBA1 gene directs the production of the glucocerebrosidase (GCase) protein, which breaks down substances called glycolipids. GBA1 mutations may lead to build-up of alpha-synuclein protein clumps.

Incidence: A measure of new disease cases arising in a population over a given period of time. Typically, incidence is measured as the number of people diagnosed per year.

Lewy Bodies: Lewy bodies are abnormal clumps of proteins, primarily consisting of alpha-synuclein, which are found in the brain cells of people with PD. Lewy bodies are the pathological hallmark of PD.

LRRK2: Mutations in the LRRK2 gene are the greatest known genetic contributor to Parkinson's disease, accounting for about one to two percent of all PD cases. LRRK2 functions as a kinase, which modifies proteins. People with the mutation have heightened LRRK2 activity, so research aims to inhibit that activity to potentially slow progression of Parkinson's.

Neurotransmitter: Specialized chemical messengers (e.g., dopamine, serotonin) that allow the nerve cells in the brain to communicate with each other. These signals dictate everyday life and functions, including movement and mood.

“Off” Periods: Times when PD symptoms return because medication is not working optimally. “Off” periods can come on gradually or suddenly and unpredictably.

Patient-reported Outcomes (PROs): Direct-from-patient, unfiltered information. PROs provide insight into the patient perspective and can complement traditional, in-person clinical trial measures to give researchers a more complete picture of PD.

Prevalence: A measurement of all individuals affected by a disease at a particular time (e.g., the number of people with Parkinson's on March, 19, 2018).

Repurposing: Taking an existing drug that has been developed (and typically FDA-approved) for one condition and using it to treat another. Clinical trials are necessary to repurpose, or reposition, a therapy to ensure it is safe and efficacious in people with Parkinson's.

Symptomatic Treatment: Addresses motor symptoms (e.g., tremor and stiffness), non-motor symptoms (e.g., cognitive problems and constipation) or medication complications (e.g., dyskinesia).