Fiscal Year 2026 Senate Appropriations Committee Subcommittee on Labor, Health and Human Services, Education and Related Agencies Appropriations Testimony

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National Institutes of Health Fiscal Year 2026 Appropriations

Chairwoman Capito, Ranking Member Baldwin, and distinguished members of the subcommittee, the Personalized Medicine Coalition (PMC) appreciates the opportunity to submit testimony on the National Institutes of Health (NIH) fiscal year (FY) 2026 appropriations and to highlight the importance of NIH-funded research to personalized medicine.

PMC is a nonprofit education and advocacy organization comprised of nearly 200 institutions from across the health care spectrum that support this growing field. In recent years, the NIH has been able to continue building the foundation of scientific knowledge underpinning personalized medicine because of strategic investments made by Congress. PMC urges the subcommittee to recognize the critical role the NIH plays in spurring discoveries that will save and improve lives, and to support the agency's need for robust funding. Renewed dedication to America's research enterprise will be essential to support further discovery of targeted health care interventions that can transform lives. As the subcommittee begins work on the **FY 2026 Labor, Health and Human Services, Education and Related Agencies appropriations bill, we request an appropriation of at least $51.303 billion for the NIH**, in addition to resources provided for the Advanced Research Projects Agency for Health. This level of funding would represent a $4.222 billion or 9 percent increase over the final FY 2025 funding level.[i]

Personalized medicine, also called precision or individualized medicine, is an evolving field in which physicians use diagnostic tests to determine which medical treatments will work best for each patient or use medical interventions to alter molecular mechanisms that impact health. By combining data from diagnostic tests with an individual's medical history, circumstances, and values, health care providers can develop targeted treatment and prevention plans with their patients. Personalized medicine promises to help detect the onset of disease, pre-empt its progression, and improve the quality, accessibility, and affordability of health care. By reinvesting in biomedical research that leads to pivotal discoveries in personalized medicine, Congress would signal to all Americans that their health continues to be a bipartisan national priority.

I. The Role of NIH in Personalized Medicine

Decades of NIH-funded biomedical research on the genetic and biological underpinnings of disease have contributed to the development of personalized treatments benefiting patients today. This research has helped inform the development of more than 300 personalized treatments[ii] and over 140,000 diagnostic products.[iii] Personalized medicines account for more than a quarter of all new drugs approved by the Food and Drug Administration (FDA) since 2015 with nearly half of new personalized treatments approved for indications outside of oncology.

Continued progress cannot be taken for granted. To ensure that scientists and innovators maintain this momentum, Congress must support policies that encourage the advancement of the field and commit to funding NIH's basic and translational research over multiple years.

II. Research Accelerating Personalized Medicine

NIH has led much of the scientific discovery for personalized medicine, which begins with basic research that generates fundamental knowledge about the molecular basis of a disease and with translational research aimed at applying that knowledge to develop a treatment or cure. Many NIH institutes and centers support research informing the development of personalized medicine approaches. Each year, more than 300,000 researchers across labs and other settings in nearly every congressional district nationwide[iv] conduct research on the most promising strategies to promote patient well-being and overcome existing and emerging health threats that patients, families, and communities face every day.[v] A robust base budget for NIH in FY 2026 would preserve the agency's ability to advance personalized medicine approaches that address rare, common, and chronic diseases.

Progress in data science and an increased understanding of disease genetics lead experts to agree that more than an estimated 10,000 rare diseases are affecting about 30 million people in the U.S. Most of these individuals are children. In all, nearly 10 percent of the U.S. population has a rare disease. In recent decades, advances in genomics have allowed researchers to identify the molecular causes of 6,500 rare diseases. Programs at the NIH's National Institute for Advancing Translational Science (NCATS) have helped shift the scientific approach to researching rare diseases from one disease at a time to many. Pooling patients, experiences, and resources promises to lead to more successful clinical trials sooner for rare disease patients. In 2023, PMC noted that nearly 60 percent of the personalized medicines approved by the FDA were for rare diseases.[vi] While this progress is encouraging, more needs to be done to accelerate the development of treatments for the 95 percent of rare diseases with no FDA-approved treatment;[vii] to strengthen the innovation of diagnostics to shorten the average 6.3-year long diagnostic odyssey patients face; and to lower the nearly $1 trillion annual economic burden of rare diseases.[viii]

Cancer care has been and will continue to be profoundly influenced by new personalized medicine approaches for detecting and treating early- and late-stage diseases. Over the past decade, personalized treatments have driven declines in mortality for some cancers and still account for more than a quarter of FDA approvals. Cancer research supported by the National Cancer Institute (NCI) played a vital role in developing targeted therapies responsible for the recent twofold decline in deaths from non-small cell lung cancer, the most common type of lung cancer. Through basic science and immunology studies, NCI also laid the foundation for the development of immune checkpoint inhibitors to enhance the body's immune response against cancer. Several of these inhibitors are now approved for treating lung cancer and have substantially improved outcomes for many people with non-small cell lung cancer. By restoring funding to the NIH, NCI could support promising research programs in pancreatic cancer, glioblastoma, and certain childhood cancers for which significant headway remains elusive, and pursue research to translate discoveries into innovative cancer prevention, screening and diagnostic practices to save more lives.

Other patients are living with highly prevalent diseases where personalized medicine can offer better diagnosis, treatments, or a cure. Alzheimer's disease and related dementias impact more than six million Americans and costs the U.S. economy $321 billion.[ix] In the last decade, NIH-funded research has allowed scientists to advance their understanding of the risk factors, genetics, and mechanisms of brain aging. Initiatives like the NIH-supported Precision Aging Network (PAN) are transforming the way we think about brain aging by convening researchers from across the country to better understand how and why people experience brain aging differently, with the goal of developing more effective treatments and interventions targeted to the individual person. Sustained funding for NIH is needed to allow the agency to support research opportunities in population studies to better prevent, identify, and treat neurological diseases.

A recent Congressional briefing hosted by PMC and the Congressional Personalized Medicine Caucus shed light on efforts to harness cutting-edge scientific approaches to strategically drive and accelerate advancements in personalizing the prevention, detection, and treatment of heart conditions. Heart disease remains the leading cause of death in the U.S. with nearly 2,500 people dying from cardiovascular disease every day. While medical advances have helped more people live longer with cardiovascular diseases, many of the risk factors that lead to these diseases, including high blood pressure and obesity, continue to grow at alarming rates.[x] The NIH's National Heart, Lung, and Blood Institute (NHLBI) has established programs to develop, test, and implement better strategies to promote cardiovascular health and prevent cardiovascular disease. NHLBI precision medicine and data science initiatives, including the BioData Catalyst and Trans-Omics for Precision Medicine (TOPMed), have unlocked capabilities in biomedical data science to transform and expand precision medicine research across the NIH, other federal agencies, and external stakeholders. New ways of collecting and converting data into information that supports and improves the health outcomes of Americans are resulting from these efforts, and facilitating better ways to detect, prevent, and treat disease.

Furthermore, an estimated 37 million Americans are living with kidney diseases, including more than 800,000 with kidney failure.[xi] People who progress to kidney failure require either dialysis or a kidney transplant. Dialysis is the most common therapy for kidney failure and has a five-year mortality rate of 60 percent. Medicare annually spends more than $50 billion, approximately 7 percent of all Medicare spending, to manage kidney failure. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) funds the vast majority of federal research on kidney diseases, and NIDDK-funded scientists have produced several major breakthroughs. Geneticists have made advances in understanding the genes that cause kidney failure, and the first medications to treat certain genetic kidney diseases progressed to late-stage clinical trials. NIDDK's Kidney Precision Medicine Project was designed to pinpoint targets for novel therapies and set the stage for the advancement of personalized medicine in kidney care, which may be possible with further investment.

Finally, to ensure that scientific breakthroughs in personalized medicine are impactful to all patients, the *All of Us™* Research Program was launched in 2018 to collect genetic and health information from 1 million volunteers as part of a decades-long research project. As of June 2025, more than 860,000 individuals are participating in the program across the United States.[xii]

All of Us™ looks for genetic variants associated with serious hereditary health conditions. It also looks for genes that can affect how a person's body processes medicines, which is information that can be used to guide which medication or dosage an individual is prescribed. In addition to participants receiving their hereditary disease risk reports revealing potentially life-changing genetic variants and those participants who received medication reports with results that could impact how their body processes drugs, *All of Us™* is enabling new discoveries over time with a goal of improving population health. *All of Us™* faces a funding cliff as the *21st Century Cures Act* authorizations expire. The success of this program in guiding more rational use of existing therapeutics and identifying efficient diagnostic strategies to inform treatment depends on additional appropriated funding for NIH in FY 2026.

III. Conclusion

Underfunding the NIH will slow the pace of scientific discovery placing the health of patients and communities at increased risk. In addition to the health benefits to patients that medical research promotes, federal investment in this lifesaving work has a multiplier effect in local and regional economies, spurs new industries, enhances the U.S.'s global competitiveness, and generates additional high-quality jobs in communities nationwide.[xiii] As Congress considers funding for FY 2026, increased investments in medical research will help the U.S. deliver breakthrough advances for patients.

PMC appreciates the opportunity to highlight some examples of NIH's contributions to the continued success of personalized medicine and hopes that you will work expeditiously to complete FY 2026 appropriations in a timely manner. We believe that federal investment in NIH-supported research will bring us closer to a future in which every patient benefits from an individualized approach to health care. We urge you and your colleagues to ensure that the NIH has the funding it needs to promote the health and well-being of all Americans.

[i] https://www.aamc.org/research/adhocgp/FY26RecommendationQA.pdf
[ii] https://www.personalizedmedicinecoalition.org/wp-content/uploads/2024/01/strategic_plan.pdf
[iii] https://onlinelibrary.wiley.com/doi/10.1002/ajmg.c.31881
[iv] https://www.nih.gov/about-nih/what-we-do/impact-nih-research/serving-society/direct-economic-contributions
[v] https://www.faseb.org/science-policy-and-advocacy/federal-funding-data
[vi] https://www.personalizedmedicinecoalition.org/wp-content/uploads/2024/02/report-3.pdf
[vii] https://everylifefoundation.org/policy-goals/
[viii] https://everylifefoundation.org/burden-study/
[ix] https://www.alz.org/alzheimers-dementia/facts-figures
[x] https://www.heart.org/en/about-us/heart-and-stroke-association-statistics
[xi] https://www.kidneyfund.org/all-about-kidneys/quick-kidney-disease-facts-and-stats
[xii] https://www.researchallofus.org/data-tools/data-snapshots/
[xiii] https://www.aamc.org/research/adhocgp/