Fiscal Year 2027 House 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 2027 Appropriations

Chairman Aderholt, Ranking Member DeLauro, 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) 2027 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. We are concerned that the President's FY 2027 budget request proposes to dramatically reduce NIH funding by roughly $6 billion, or 12 percent. Doing so would undermine progress on innovative research to develop treatments and cures for patients in this country. You and other bipartisan leaders in Congress have recognized the importance of federal investments in medical research, allowing NIH to support science that leads to healthier patients. **PMC urges the subcommittee to provide an appropriation of at least $51.303 billion for the NIH in FY 2027,** in addition to resources provided for the Advanced Research Projects Agency for Health. This level of funding would allow the NIH to continue building the foundation of scientific knowledge underpinning personalized medicine.[i]

I. The Role of NIH in Personalized Medicine

Personalized 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. 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. Since 2015 personalized treatments have driven declines in mortality for some cancers and are now improving treatment of a growing number of diseases outside of oncology. Continued progress cannot be taken for granted. To ensure that scientists and innovators maintain this momentum, Congress must 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. A robust base budget for NIH in FY 2027 would preserve the agency's

ability improve the health of all Americans by advancing personalized medicine approaches that address common, chronic, and rare diseases.

Cancer is a highly prevalent disease that requires an in-depth understanding of how genetic, physiological, behavioral, and environmental factors contribute to its development. Discoveries in basic scientific research on the initiation, growth, survival, and spread of cancer cells in the body have been, and continue to be, essential for progress. Research teams funded by National Cancer Institute (NCI) have studied tumors at the single cell level and published studies exploring the role of the tumor microenvironment and immune system in promoting the spread of cancer and its resistance to treatment. Researchers also mapped the trajectory of precancerous colorectal tissues toward cancer by measuring the contributions of multiple molecular and cellular events. A second phase would further build on these results for expanded organ and tissue types. Furthermore, the risk of developing cancer is influenced by the interplay of a variety of factors. Understanding the interactions among genetic, environmental, and health factors will improve the ability of scientists to prevent, diagnose, and treat cancers. For example, NCI-funded scientists recently identified a group of genetic changes that are likely involved in the development of cancer in children. They found that genomic changes affecting large pieces of DNA present at birth and typically inherited from a parent contribute to an estimated one to six percent of pediatric solid tumors. These findings provided a better understanding of the earliest biology leading to childhood cancer.[ii]

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. For more than 50 years, NCI-supported research has played a vital role in the development of treatments for people with cancer. One NCI-funded clinical trial recently found that a new form of tumor infiltrating lymphocyte (TIL) therapy, a form of personalized cancer immunotherapy, dramatically improved treatment effectiveness in patients with metastatic gastrointestinal cancers. NCI research also played a vital role in developing targeted therapies responsible for declines in mortality from the most common type of lung cancer and immune checkpoint inhibitors to enhance the body's immune response against cancer. Several of these inhibitors are now FDA approved for and have substantially improved outcomes for adult patients. Another large NCI-supported trial showed that children with acute lymphoblastic leukemia (ALL) had a substantial improvement in disease-free survival when treated with standard chemotherapy combined with the immunotherapy blinatumomab. This is now expected to become part of initial treatment for many children diagnosed with ALL. By restoring funding to the NIH, NCI could support more promising research programs for adult and pediatric cancers like these for which significant headway remains elusive. NCI could use additional resources to pursue research that translates discoveries into innovative cancer prevention, screening and diagnostic practices to save more lives.

Many patients are living with other highly prevalent diseases where personalized medicine can offer better diagnosis, treatments, or a cure. Alzheimer's disease and related dementias (AD/ARD) impact more than six million Americans and costs the U.S. economy $321 billion.[iii] In the last decade, NIH-funded research has allowed scientists to advance their understanding of the risk factors, genetics, and mechanisms of brain aging. This research has significantly improved the ability to diagnose AD/ARD at earlier stages with tests that are more

reliable, more affordable, and less invasive. More sensitive diagnostics and clinical biomarkers to identify individuals living with early stages of mixed dementia, where brain changes are caused by multiple, co-occurring disease pathways are still needed. With increased investment, NIH could expand research on AD/ARD biomarkers to improve the detection of different dementia pathologies across the disease trajectory and improve the dissemination of the latest research on diagnostics to clinicians, which would facilitate stage- and dementia-specific personalized treatment planning.[iv]

NIH initiatives have increased knowledge of the biological pathways and behaviors that contribute to Alzheimer's disease onset, and as a result, there is a diverse range of identified drug candidates and behavioral modifications that have the potential to prevent and treat dementia. With increased funding, NIH could explore new therapeutic modalities including translational efforts to develop new genomic therapies for AD/ARD. This work would be built upon NIH-funded research demonstrating the potential of genomic therapy for several neurological disorders and gene editing in stem cells to effectively correct the most common genetic mutation associated with frontotemporal dementia. NIH could grow its genomic therapy portfolio to advance genomic approaches to prevent and treat AD/ARD. This would further shift the field toward a precision medicine approach with patient-specific treatments.

Congressional briefings 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 chronic heart conditions and kidney disease. 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, continue to grow at alarming rates.[v] 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 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.[vi] People who progress to kidney failure require either dialysis or a kidney transplant. Medicare annually spends more than $50 billion, approximately 7 percent of all Medicare spending, to manage kidney failure but currently federal research investment for kidney health equates to less than 1 percent of Medicare fee-for-service expenditures for Americans with kidney disease. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) funds the vast majority of federal research on kidney diseases. 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. NIDDK-funded scientists have made advances in understanding the genes that cause kidney failure and progressed the first medications to treat certain genetic kidney diseases into late-stage clinical trials. With further investment, NIH could expand research to better define kidney

disease mechanisms and utilize genetic tools to identify new therapeutic targets, develop better models of human disease, and test cell-specific drug delivery systems and gene editing approaches for this costly and often deadly chronic disease.

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. Programs at the NIH's National Institute for Advancing Translational Science (NCATS) are prioritizing gene-targeted therapies to help develop treatments for multiple rare diseases at the same time and to decrease time and costs for therapy development by creating and making high quality tools available. In 2025, NCATS celebrated the groundbreaking treatment of Baby KJ Muldoon who was diagnosed with the rare condition carbamoyl phosphate synthetase 1 (CPS1) deficiency shortly after birth. In six months, a NIH-supported research team developed and safely delivered a personalized gene editing therapy to treat this life-threatening, incurable genetic disease by correcting a specific gene mutation in the baby's liver cells. This opens the possibility of creating personalized treatments in other parts of the body. With improved screening, NCATS is working to improve diagnosis earlier treatment for children like Baby JK.[vii]

Finally, the NIH launched a decades-long research program called *All of Us*™ in 2018 to be the largest disease-neutral research dataset in the United States. With more than 878,000 participants, *All of Us*™ has yielded insights into assessing personalized chronic disease risks, and how genes influence how a person's body processes medicines, which can be used to guide personalized therapeutic choices. In addition to participants receiving life-changing information to manage their health, *All of Us*™ research infrastructure investments are making genomic research accessible to more scientists, with more than 22,000 researchers and 1,300 scientific publications to date. As *21st Century Cures Act* funding expires for *All of Us*™ at the end of FY 2026, appropriations support for the program under the NIH Office of the Director would build on its successes in guiding more rational use of existing therapeutics and identifying efficient diagnostic strategies to inform personalized treatment strategies.

III. Conclusion

PMC appreciates the opportunity to highlight some examples of NIH's contributions to the continued growth of personalized medicine. Now is not the time to diminish NIH's leadership in medical research and stall progress on the next generation of groundbreaking discoveries. We believe that federal investment in NIH-supported research is essential to achieving a future in which every patient benefits from an individualized approach to health care. PMC urges you and your colleagues to ensure that the NIH has the funding it needs to promote the health and well-being of all Americans.

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[i] https://www.fundnih.org/our-recommendation
[ii] https://ncats.nih.gov/sites/default/files/2026-04/NCATS_FY-2027_CJ.pdf
[iii] https://www.alz.org/alzheimers-dementia/facts-figures
[iv] https://www.nia.nih.gov/sites/default/files/2025-09/fy-2027-nih-professional-judgment-budget-alzheimers.pdf
[v] https://www.heart.org/en/about-us/heart-and-stroke-association-statistics
[vi] https://www.kidneyfund.org/all-about-kidneys/quick-kidney-disease-facts-and-stats
[vii] https://ncats.nih.gov/sites/default/files/2026-04/NCATS_FY-2027_CJ.pdf