May 14, 2025

The Honorable Mike Johnson Speaker U.S. House of Representatives 568 Cannon House Office Building Washington, DC 20515

The Honorable Robert Aderholt U.S. House of Representatives Chair, House Appropriations Subcommittee on Labor-HHS 272 Cannon House Office Building Washington, DC 20515 The Honorable Hakeem Jeffries Minority Leader U.S. House of Representatives 2267 Rayburn House Office Building Washington, DC 20515

The Honorable Rosa DeLauro U.S. House of Representatives Ranking Member, House Appropriations Committee; Ranking Member, Subcommittee on Labor-HHS 2413 Rayburn House Office Building Washington, DC 20510

Dear Speaker Johnson, Chair Aderholt, Leader Jeffries and Ranking Member DeLauro,

We, the undersigned organizations, write to express our deep concern for our nation's biomedical research institutions and infrastructure, and to call upon Congress to stand up for the United States' global scientific leadership and our relentless search for cures by demanding an immediate reversal of the egregious and harmful policy changes directed at these institutions, including the NIH. Within a span of a few months, the administration has proposed or implemented sweeping policy changes that have destabilized research programs nationwide; collectively, these actions have begun and will continue to erode the NIH's status as the world's foremost driver of biomedical innovation and prevent our country's research institutions from delivering scientific breakthroughs to patients who are desperately waiting for them. These efforts threaten to undermine the NIH, the entirety of the United States biomedical research ecosystem, and the lives of people across the country.

Delays and cancellations of study sections and advisory council meetings have prevented the awarding and disbursement of NIH grant funds, with 6,000 fewer grants and over \$2 billion less in grant funding awarded compared to the same time period in past years.¹ Mass reductions in force will diminish the agency's ability to review and administer grants, reduce the amount of research and clinical trials conducted, and erode decades of critical institutional knowledge. A significant decrease, roughly 35%, in contract spending for both infrastructure and specialized technical functions will further hinder the ability of the NIH to operate.² And, as detrimental as these actions have been, they pale in comparison to the possibility of a 40% reduction in overall NIH funding as proposed by the 2026 HHS budget, which would bring the NIH budget back to FY2003 funding levels.³

As these changes are implemented, we are witnessing an unprecedented and consequential deterioration in the vital, productive relationship between the NIH and United States research institutions. Enacting abrupt, drastic limitations on reimbursement rates for facilities and administrative costs, including on existing grants with prenegotiated rates⁴, creates budget shortfalls that universities cannot compensate for, especially in the short-

¹ https://www.statnews.com/2025/04/24/trump-100-days-nih-new-grants-cut/?utm_campaign=pharmalot&utm_medium=email&_hsenc=p2ANqtz--Y4ro0zj7irDhls6kguRKZu0TCZHVBkbD99-

⁰kewl_TrnXSw9JwupHhl5JljkVmsE0iZSge78aswS0Tr3qZqcH0le9aw&_hsmi=358383014&utm_content=358383014&utm_source=hs_email ² https://www.science.org/content/article/nih-under-orders-cancel-2-6-billion-contracts

³ Congressional Research Service. (2024). *National Institutes of Health (NIH) Funding: FY1996-FY2025*. https://sgp.fas.org/crs/misc/R43341.pdf ⁴https://grants.nih.gov/grants/guide/notice-files/NOT-OD-25-068.html

term. NIH funding is also being used as a tool to pressure higher education institutions whose institutional policies do not align with the views of the administration. This includes recent changes to grant conditions⁵ that would require universities to alter policies unrelated to their NIH grants and dismantle completely separate programs in order to receive grant funds. These and similar actions go against the spirit of scientific merit and academic freedom that the NIH is meant to support.

But when we center our conversations around the policy implications of radical alterations to the NIH, it is easy to lose sight of and distance ourselves from the large-scale human toll of these actions. Recent analysis indicates that almost every single drug approval between 2010 and 2019—354 out of 356, nearly a quarter of which were first-to-target products—was associated with NIH-funded research.⁶ This includes gene therapies that prevent babies with spinal muscular atrophy from dying in infancy, small-molecule therapies that have extended the lives of people with cystic fibrosis by decades, CAR-T cell therapies able to treat hematological malignancies in patients that haven't responded to other treatments, inhalable naloxone used to treat opioid overdose, and hundreds of others, just over the course of a single decade.

Without the NIH, these therapies don't exist. Without the NIH, we don't have the *people* that those therapies have saved–our parents, our children, our siblings and friends and loved ones. In its 138 years of existence, the NIH has been responsible for saving or bettering more lives than we will likely ever be able to calculate. It is our moral imperative to ensure that the NIH can continue to perform that function.

This is an existential threat to the work that our organizations are dedicated to: the vigorous pursuit of cures for devastating diseases and richer, fuller, longer lives for those who live with them. Every day that we continue down this path sets us back years, if not decades. The administration must immediately take the steps necessary to remedy the damage that has already been done to the United States research system and prevent further harm; to seize the opportunity to secure the United States' position as the global leader in biomedical innovation; and to ensure that patients—not politics—remain our priority. We call on you, Congress, a coequal branch of government, to vigorously protect the biomedical research ecosystem that you have supported for decades. Our lives depend on it.

Sincerely,

Academy of Oncology Nurse & Patient Navigators (AONN+) Academy of Physicians in Clinical Research American College of Medical Genetics and Genomics American Epilepsy Society American Heart Association American Society for Transplantation and Cellular Therapy Arthritis Foundation Association of Oncology Social Work Children's Cancer Cause Coalition for National Trauma Research Crohn's & Colitis Foundation CURE Epilepsy Cystic Fibrosis Foundation

⁵ https://grants.nih.gov/grants/guide/notice-files/NOT-OD-25-090.html

⁶ Galkina Cleary E, Jackson MJ, Zhou EW, Ledley FD. Comparison of Research Spending on New Drug Approvals by the National Institutes of Health vs the Pharmaceutical Industry, 2010-2019. JAMA Health Forum. 2023;4(4):e230511. doi:10.1001/jamahealthforum.2023.0511

Danny Did Epilepsy Foundation Dravet Syndrome Foundation **Epilepsy Alliance America Epilepsy Foundation of America** Friends of Cancer Research GO2 for Lung Cancer Hemophilia Federation of America International Myeloma Foundation Lennox-Gastaut Syndrome (LGS) Foundation Lymphoma Research Foundation Muscular Dystrophy Association National Association of Epilepsy Centers National Ataxia Foundation National Coalition for Cancer Survivorship National Health Council National Multiple Sclerosis Society NDRI Pulmonary Hypertension Association Society for Immunotherapy of Cancer The Leukemia & Lymphoma Society