November 21, 2024

The Honorable Tammy Baldwin Chair Subcommittee on Labor, Health and Human Services, Education, and Related Agencies Committee on Appropriations U.S. Senate Washington, DC 20510

The Honorable Robert Aderholt Chair Subcommittee on Labor, Health and Human Services, Education, and Related Agencies Committee on Appropriations U.S. House of Representatives Washington, DC 20515 The Honorable Shelley Moore Capito Ranking Member Subcommittee on Labor, Health and Human Services, Education, and Related Agencies Committee on Appropriations U.S. Senate Washington, DC 20510

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Committee on Appropriations
U.S. House of Representatives
Washington, DC 2051

Dear Chair Baldwin, Ranking Member Capito, Chair Aderholt, and Ranking Member DeLauro,

We, the undersigned organizations, are writing to express our strong support for the National Institutes of Health (NIH) Brain Research Through Advancing Innovative Neurotechnologies (BRAIN) Initiative and the NIH *All of Us* Research Program. **As Congress completes negotiations on FY 2025 appropriations we respectfully request that you maintain or exceed the total Senate-proposed funding levels of \$680.4 million for the BRAIN Initiative and \$541 million for the** *All of Us* **Research Program for Fiscal Year 2025. Each of these programs is supported by the 21st Century Cures Innovation Fund. With diminishing resources available from the Innovation Fund, it is critical that Congress provide sufficient discretionary appropriations to allow these two groundbreaking programs to continue to make revolutionary advances that can improve brain and overall health outcomes.**

BRAIN Initiative

Despite tremendous progress, brain disorders, such as Alzheimer's disease, Parkinson's disease, autism, epilepsy, schizophrenia, depression, and traumatic brain injury, are projected to be some of the most disabling and costly chronic diseases in the 21st century. One in three Americans will have a brain or nervous system disorder sometime in their life and the cost of treating neurological disorders is nearly \$1.5 trillion each year. The BRAIN Initiative is revolutionizing our understanding of the brain and offering hope for the millions of individuals impacted by brain diseases and conditions.

Significant strides in neuroscience research have been made in the past few years. Some examples of this include advancements in Deep Brain Simulation (DBS), which have provided life-changing improvements for patients with severe depression, obsessive-compulsive disorder,

and traumatic brain injury (TBI), and more recently, a <u>study</u> that showed success in demonstrating that a computerized brain implant can decode internal speech.

Another recent advancement includes the monumental neuroscience news that the BRAIN Initiative Cell Census Network (BICCN) program, for the first time ever, created a cell atlas of a whole mouse brain and a draft cell atlas of the human brain. These multidisciplinary findings bring researchers closer to understanding the brain's cellular makeup and how brain disorders develop, progress, and are best treated and provide important tools for researchers to continue to make discoveries.

Despite continued progress and growing opportunity, The BRAIN Initiative has faced decreased funding in recent years, reducing its capabilities. Due to the drop in 21st Century Cures funding and the lack of additional discretionary funding, the BRAIN Initiative received only \$402 million in FY 2024—roughly a 40% cut from the previous year's appropriation. The significant funding reduction has impacted the BRAIN Initiative's capacity to support potential groundbreaking research, with only 50% of proposals being funded in FY 2024. With flat discretionary funding in FY 2025, the BRAIN Initiative will face an additional \$81 million cut, resulting in fewer than 20% of research proposals being funded. This would impede new clinical neurologic advancement for thousands of those with debilitating brain diseases and conditions. Ultimately, we strongly encourage you to further your support for the BRAIN Initiative to ensure that these exciting advancements in neuroscience continue.

All of Us Research Program

The *All of Us* Research Program is designed to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, environment, and biology, the program aims to uncover paths toward delivering precision medicine—tailored to the individual.

The program's diverse cohort is critical to its success. Historically, medical research has not always been representative of the population at large, leading to gaps in knowledge and care. *All of Us* is committed to including participants from all walks of life, especially those who have been underrepresented in biomedical research. This inclusivity is essential for ensuring that the findings of the research are applicable to everyone and can lead to more precise healthcare solutions based on individual differences and improved public health outcomes.

The program is still working towards the goal of enrolling one million participants, yet it is already delivering results to participants and the scientific/medical community. More than 100,000 participants have received personalized health-related DNA reports from the program, with information about hereditary disease risk and how their bodies process certain medications. Through these reports, *All of Us* provided potentially life-saving information about the genetic risk of cancers, heart disease, or other conditions to more than 2,000 participants already. Researchers and institutions from all fifty states have signed up to utilize the *All of Us* dataset. As a result, researchers have initiated more than 10,000 projects using *All of Us* data and published hundreds of papers in peer-reviewed journals – on cancer, diabetes, kidney health, heart disease, depression, glaucoma, COVID-19, alcohol and substance use, physical activity, and other topics.

Just recently, the program reported the discovery of 275 million previously unknown genetic variants from data shared by *All of Us* participants, a massive tranche that may offer new clues about genetic influences on health and disease.

Much more work remains before the full potential of *All of Us* can be realized. This includes the active recruitment of children into the cohort to improve the health of children and to better understand conditions that onset in adulthood but are rooted in childhood. However, decreased funding in Fiscal Year 2024 now threatens the program and the scientific breakthroughs envisioned for the program. In FY24, *All of Us* received \$357 million representing a decrease of \$184 million (34%) compared to last year's appropriation. According to the program's leadership, this decrease in funding will have a substantial impact, including: a decrease in the rate of new enrollments, a delay in the launch of pediatric enrollment, and a slowing of new data collection.

Conclusion

Further funding cuts for the Brain Initiative and the *All of Us* Research Program in FY 2025 will limit their ability to advance research, support new studies, spark discoveries that revolutionize understanding of brain function, and ensure researchers have data that is representative of the entire population. As champions of the BRAIN Initiative and the *All of Us* Research Program, we urge you to support these important programs in FY 2025 to ensure continued innovative research and improved health for all Americans. Thank you for your attention to this important matter and for your continued commitment to advancing medical research and public health. If you have questions or would like further information, please reach out to Meghan Riley at mriley@dc-crd.com.

Sincerely,

American Brain Coalition A Nation of Hope **ACCESS** Alliance for Aging Research Alliance for Headache Disorders Advocacy Alliance for Patient Access American Academy of Neurological Surgery American Academy of Neurology American Association of Colleges of Nursing American Association of Colleges of Pharmacy American Association of Neurological Surgeons American Association on Health & Disability American Clinical Neurophysiology Society American College of Clinical Pharmacy American College of Neuropsychopharmacology American Epilepsy Society

American Neurological Association

American Public Health Association

American Society of Human Genetics

American Stroke Association

Anxiety and Depression Association of America

Area Health Education Center for Western Washington

Asian Health Coalition

Association of University Professors of Neurology

Baker Street Cares Foundation

BCI Pioneers Coalition

BDSRA Foundation

Brain Aneurysm Foundation

Brain Injury Association of America

Brown University

CACNA1A Foundation

Canavan Foundation

Carilion Clinic/ Virginia Tech Carilion School of Medicine

Cerebral Palsy Research Network

Childhood Brain Tumor Foundation

Chronic Migraine Awareness, Inc.

Coalition to Cure CHD2

Congress of Neurological Surgeons

Council on Social Work Education

CSNK2A1 Foundation

Cure Alzheimer's Fund

Cure Brain Disease

CURE Epilepsy

CURE GABA-A

cureCADASIL

CureSHANK

Danny Did Foundation

Dementia Society of America

Dillard University Community Relations

Dravet Syndrome Foundation

Dup15q Alliance

DYNC1H1 Association

Dyspraxia DCD America

Epilepsies Action Network (EAN)

Epilepsy Alliance America

Epilepsy Foundation of America

Epilepsy Leadership Council

FAM177A1 Research Fund

FamilieSCN2A Foundation

FND Hope

Friedman Brain Institute, Icahn Mount Sinai

Friedreich's Ataxia Research Alliance (FARA)

GABA-A Alliance

GRIN2B Foundation

Harvard University

Headache and Migraine Policy Forum

Hope for HIE

Hope for Hypothalamic Hamartomas

Huntington's Disease Society of America

Hydrocephalus Association

IEEE Brain

INADcure Foundation

International Alliance for Pediatric Stroke

International BCI Society

International Bipolar Foundation

International Essential Tremor Foundation

International Foundation for CDKL5 Research

International OCD Foundation

Kappa Alpha Psi Fraternity Inc

KCNQ2 Cure Alliance

Lakeshore Foundation

LEAD Coalition (Leaders Engaged on Alzheimer's Disease)

Lennox-Gastaut Syndrome (LGS) Foundation

Lundbeck Pharmaceuticals LLC

M-CM Network

Maryland Rural Health Association

McLean Hospital

MdDS Balance Disorder Foundation

Medical Technology Enterprise Consortium (MTEC)

Miles for Migraine

MLD Foundation

Movement Disorders Policy Coalition

Nash Family Center for Advanced Circuit Therapeutics at Mount Sinai

National Alliance on Mental Illness

National Association for Biomedical Research

National Association of Hispanic Nurses

National Association of State Head Injury Administrators

National Association of State Mental Health Program Directors

National Ataxia Foundation

National Headache Foundation

National Hispanic Medical Association

National Institute of Mental Health

National Multiple Sclerosis Society

National Network of Depression Centers

National Rural Health Association

Neurotech Network

New Orleans Council on Aging

New York University

NORSE Institute

North American Neuromodulation Society

Northwest Noggin

NR2F1 Foundation

Otsuka America Pharmaceutical, Inc.

Parkinson's Foundation

Pediatric Epilepsy Research Consortium

Phelan-McDermid Syndrome Foundation

PURA Syndrome Foundation

Rare Epilepsy Network (REN) Coordinating Committee

Rural Minds

SCDAI Sickle Cell Disease Association of Illinois

Seven Star Academy Inc

Society for Neuroscience

Society for Women's Health Research

Society of Neurological Surgeons

South Carolina Advocates for Epilepsy

Southern University at Shreveport

STXBP1 Foundation

SynGAP Research Fund dba Cure SYNGAP1

TBF for Brain Aneurysm Prevention

The Association for Frontotemporal Degeneration

The Brain Donor Project

The Cute Syndrome Foundation

The Kennedy Forum

The Michael J. Fox Foundation for Parkinson's Research

The Salk Institute

The STARR Coalition

The Sturge-Weber Foundation

Treatment Advocacy Center

TSC Alliance

UnidosUS

University of Illinois College of Medicine

University of Kansas Medical Center

University of Nebraska Medical Center

University of Pittsburgh

v-ATPase Alliance

Vanderbilt University Medical Center Walt's Waltz YWHAG Research Foundation

cc: The Honorable Patty Murray, Chair, U.S. Senate Committee on Appropriations
The Honorable Susan Collins, Vice Chair, U.S. Senate Committee on Appropriations
The Honorable Tom Cole, Chair, U.S. House Committee on Appropriations