



THE AD HOC GROUP FOR MEDICAL RESEARCH

February 3, 2025

Dear Member of Congress:

As the 119th Congress begins, over 300 undersigned members of the Ad Hoc Group for Medical Research wish to welcome you. We invite you and your staff to consider this coalition as a valuable resource regarding our nation's premier medical research agency the National Institutes of Health (NIH), and its impact on improving the health of patients across the nation. The Ad Hoc Group for Medical Research, founded in 1982, is a coalition of patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry, dedicated to enhancing the federal investment in biomedical, behavioral, social, and population-based research supported by NIH.

Nearly every medication, diagnostic, and other intervention in practice today has its origins in NIH-funded research. Today, NIH investment takes place in every state and in nearly every [congressional district](#). NIH seeks to drive medical breakthroughs that will benefit patients nationwide, advance potential treatments and preventive strategies for cancer and Alzheimer's, improve maternal health, and develop countermeasures for persistent or emerging health threats. In 2024 alone, NIH research supported the development of a blood test that identified Alzheimer's disease correctly in older adults with nearly 90 percent accuracy. Such tests assist in speedier diagnoses and improve access to earlier treatments - saving lives. NIH-supported researchers developed a brain-computer interface that allowed a man to communicate after his ability to speak was impaired by amyotrophic lateral sclerosis (ALS). NIH-supported research also developed 3D maps of cancer which have provided critical information on how tumors develop, spread, and respond to treatments.

In addition to improving patients' health, a robust, reliable investment in scientific discovery is crucial to strengthening the economy in the near- and long-term and maintaining our nation's global dominance in medical discoveries. Through NIH, the federal government plays an irreplaceable role in supporting biomedical research that is inherently inefficient for industry to conduct but is essential to inform our fundamental understanding of medicine. More than 80 percent of the NIH's budget supports research in all 50 states and D.C., as well as U.S. territories, at medical schools, teaching hospitals, universities, and research institutes, which often are among the largest employers in their respective communities. In fiscal year (FY) 2023, federal support of medical research [directly and indirectly supported](#) over 400,000 jobs and produced nearly \$93 billion in new economic activity nationwide – or \$2.46 of economic activity for every \$1 of research funding. Moreover, as the world's premier public funder of medical research, the NIH plays an important role in our nation's international leadership, drawing top-tier talent from across the world to benefit the health and wellbeing of American communities and patients.

Even with the longstanding bipartisan support for the groundbreaking research supported by NIH, the agency is only able to fund approximately 1 in every 5 promising proposals, leaving potentially lifesaving science on the table, a challenge that is compounded when funding does

not keep pace with inflation. In November 2024, over 400 organizations across the NIH stakeholder community recommended at least the Senate Appropriations Committee approved-level of \$48.9 billion for NIH in FY 2025. This investment would help expand the potential for new cures and other interventions for patients and their families, fully capitalize on scientific opportunity, and ensure that NIH remains the global leader in medical research. Underinvestment in research supporting cures and treatments for patients not only harms the health of Americans, but also weakens our international leadership and status as a premier destination for global research talent.

Our community is grateful for the longstanding bipartisan and bicameral commitment to ensure that investment in NIH remains a national priority. We look forward to working together in the 119th Congress and thank you again for your leadership and prioritization of the work that brings hope to patients and their families.

Sincerely,

5p- Society

Academy for Radiology and Biomedical Imaging Research

AcademyHealth

Accessia Health

ACT for NIH

Akari Foundation

AliveandKick'n: Living with Lynch Syndrome

Alliance for Aging Research

Alliance to Solve PANS & Immune-Related Encephalopathies (ASPIRE)

Alpha-1 Foundation

ALS Association

Alzheimer's Association

Alzheimer's Impact Movement

American Academy of Neurology

American Academy of Nursing

American Association for Respiratory Care

American Association for Cancer Research

American Association for Dental, Oral, and Craniofacial Research

American Association for Respiratory Care

American Association for the Advancement of Science

American Association for the Study of Liver Diseases

American Association for Women in Radiology

American Association of Colleges of Nursing

American Association of Colleges of Pharmacy (AACP)

American Association of Neurological Surgeons

American Association of Neuromuscular & Electrodiagnostic Medicine

American Association of Physicists in Medicine

American Association of Veterinary Medical Colleges

American Brain Coalition

American Cancer Society Cancer Action Network (ACS CAN)

American College of Neuropsychopharmacology

American College of Radiology

American College of Rheumatology

American College of Surgeons

American Council on Education

American Federation for Aging Research
American Gastroenterological Association
American Geriatrics Society
American Heart Association
American Institute for Medical and Biological Engineering (AIMBE)
American Lung Association
American Massage Therapy Association
American Neurological Association
American Physiological Society
American Psychological Association Services
American Sexual Health Association
American Sexually Transmitted Diseases Association
American Society for Cell Biology
American Society for Investigative Pathology
American Society for Microbiology
American Society for Nutrition
American Society of Anesthesiologists
American Society of Gene & Cell Therapy
American Society of Hematology
American Society of Human Genetics
American Society of Nephrology
American Society of Pediatric Nephrology
American Society of Tropical Medicine and Hygiene
American Statistical Association
American Thoracic Society
American Urological Association (AUA)
Americans for Medical Progress
Angelman Syndrome Foundation
Asbestos Disease Awareness Organization (ADAO)
Associated Medical Schools of New York
Association for Academic Pathology
Association for Psychological Science
Association of Academic Health Sciences Libraries (AAHSL)
Association of American Cancer Institutes
Association of American Medical Colleges
Association of American Universities
Association of Bioethics Program Directors
Association of Independent Research Institutes
Association of Minority Health Professions Schools
Association of Population Centers
Association of Public and Land-Grant Universities, Associate Vice President for Research Policy and Gov Affairs
Association of Schools and Colleges of Optometry
Association of Schools and Programs of Public Health
Association of University Anesthesiologists
Autism Speaks
Barth Syndrome Foundation
Baylor College of Medicine
BDSRA Foundation
Biophysical Society
Boston Medical Center Health System

Breakthrough T1D (formerly JDRF)
Broad Institute of MIT and Harvard
CACNA1A Foundation
Cancer and Careers
Case Western Reserve University School of Medicine
Cedars-Sinai
Celiac Disease Foundation
Center for Endometriosis Care
Center for Optimal Aging, Marymount University
Children's Hospital Association
Cholangiocarcinoma Foundation
Chris "CJ" Johnson Foundation Inc.
ChristianaCare
Christopher & Dana Reeve Foundation
Cleveland Clinic
Coalition for Clinical and Translational Science
Coalition of Skin Diseases
Coalition to Cure CHD2
Columbia University
Community Oncology Alliance (COA)
Conference of Boston Teaching Hospitals
Congenital Hyperinsulinism International
Congress of Neurological Surgeons
Cornell University
Council on Social Work Education
COVID-19 Longhailer Advocacy Project
Cribs for Kids, Inc.
CSNK2A1 Foundation
CUNY School of Medicine
CURE Epilepsy
Cure HHT
Cystic Fibrosis Foundation
Dana-Farber Cancer Institute
Dartmouth Health
Deadliest Cancers Coalition
Debbie's Dream Foundation: Curing Stomach Cancer
Dell Medical School at the University of Texas at Austin
Dravet Syndrome Foundation
Duke Health
Duke University
Dysautonomia International
Dystonia Medical Research Foundation
ECAN Esophageal Cancer Action Network
ECU Health & ECU Brody School of Medicine
Emory
Endocrine Society
Entomological Society of America
Epilepsy Foundation of America
Family Caregiver Alliance
Family Voices of California
Federation of American Societies for Experimental Biology (FASEB)

Federation of Associations in Behavioral & Brain Sciences
Focused Ultrasound Foundation
FORCE: Facing Our Risk of Cancer Empowered
Foundation for Angelman Syndrome Therapeutics
Foundation for Biomedical Research
Foundation for Sarcoidosis Research
Fox Chase Cancer Center
Friedreich's Ataxia Research Alliance (FARA)
Friends of the National Institute on Aging
Gaucher Community Alliance
GBS|CIDP Foundation International
Genetic Alliance
Global Liver Institute
Good Days
Harvard University
Head for the Cure Foundation
HealthyWomen
Henry Ford Health
Hereditary Angioedema Association
Hermansky-Pudlak Syndrome Network
HIV Medicine Association
Hope for HIE
Indiana University
Infectious Diseases Society of America
International Bipolar Foundation
International Foundation for CDKL5 Research
International Foundation for Gastrointestinal Disorders
International Rett Syndrome Foundation
International Society for Magnetic Resonance in Medicine (ISMRM)
International WAGR Syndrome Association
Interstitial Cystitis Association
Joey's Wings Foundation
Johns Hopkins University & Medicine
Keck Medicine of USC
Kidney Cancer Association
kids with heart natl assn for children's heart disorders, inc
La Jolla Institute for Immunology
Lasker Foundation
LEAD Coalition (Leaders Engaged on Alzheimer's Disease)
Let's Talk UTI, Inc.
Lewis Katz School of Medicine at Temple University
Lifespan Research Institute
Look. Foundation
Lupus Foundation of America
Lymphatic Education & Research Network
M-CM Network
March of Dimes
Marymount University
Mass General Brigham
Massachusetts Society for Medical Research
MEAction

Medical College of Wisconsin
Medical Image Perception Society
Memorial Sloan Kettering
MemorialCare Health System
Men's Health Network
Michigan State University
Mission MSA
MitoAction
MLD Foundation
Morehouse School of Medicine
Mount Sinai Health System
Mucopolidosis Type IV Foundation
National Alliance for Eye and Vision Research
National Alliance for PANS/PANDAS Action
National Alliance on Mental Illness
National Association for Biomedical Research
National Association For Continence
National Association of State Alcohol and Drug Agency Directors
National Association of Veterans' Research and Education Foundations (NAVREF)
National Eczema Association
National Fragile X Foundation
National Health Council
National Kidney Foundation
National Multiple Sclerosis Society
National Scleroderma Foundation
National Society of Genetic Counselors
Neuroimmune Foundation
New Jersey Association for Biomedical Research
New York Genome Center
New York Medical College
New York State Academic Dental Centers
NORSE Institute
North American Vascular Biology Organization
North Carolina Association for Biomedical Research
Northwest Association for Biomedical Research
Nutrition and Medical Foods Coalition
NYU Langone Health
Old Dominion University
Oregon Health & Science University
Pancreatic Cancer Action Network (PanCAN)
Parent Project Muscular Dystrophy
Patient-Led Research Collaborative
Penn State Health
Pennsylvania Society for Biomedical Research
Phelan-McDermid Syndrome Foundation
PINK Concussions
PKD Foundation
Platelet Disorder Support Association
Population Association of America
Prevent Blindness
Project Sleep

Propionic Acidemia Foundation
Prostate Cancer Foundation (PCF)
Pulmonary Fibrosis Foundation
Pulmonary Hypertension Association
PXE International
Recurrent Pregnancy Loss Association
Restless Legs Syndrome Foundation
Rutgers, The State University of New Jersey
Safe Kids Worldwide
Sjögren's Foundation, Inc.
Sleep Research Society
Society for Imaging Informatics in Medicine
Society for Neuroscience
Society for Reproductive Investigation
Society for Women's Health Research
Society of Academic Associations of Anesthesiology and Perioperative Medicine (SAAAPM)
Society of General Internal Medicine
Society of Interventional Radiology
Society of Nuclear Medicine and Molecular Imaging
Society of PAs in Genetics & Genomics
Society of Radiologists in Ultrasound
Susan G. Komen
Texas Biomedical Research Institute
Texas Society for Biomedical Research
The Alex Manfull Fund
The Alliance for Longevity Initiatives
The Coalition Against Pediatric Pain
The Consortium of Social Science Associations
The George Washington University
The Judy Nicholson Foundation
The Life Raft Group
The Louisa Adelynn Johnson Fund for Complex Disease
The Michael J. Fox Foundation for Parkinson's Research
The National Pancreas Foundation
The STARR Coalition
The Sturge-Weber Foundation
The University of Texas Medical Branch at Galveston (UTMB)
Triage Cancer
TSC Alliance
Tulane University
Tuskegee University College of Veterinary Medicine
UCLA
UMass Chan Medical School
Univeristy of Utah Health
University at Buffalo
University of California, Irvine
University of Chicago Medical Center
University of Cincinnati
University of Colorado
University of Colorado Anschutz Medical Campus
University of Colorado Boulder

University of Colorado Colorado Springs
University of Colorado Denver
University of Hawai'i John A. Burns School of Medicine
University of Houston System
University of Maryland, Baltimore
University of Miami Leonard M. Miller School of Medicine
University of Nevada, Las Vegas-Kirk Kerkorian School of Medicine
University of North Carolina at Chapel Hill
University of Rochester
University of Washington
UsAgainstAlzheimer's
Usher 1F Collaborative
Usher Syndrome Coalition
UVA Health
v-ATPase Alliance
Vanderbilt University
Vanderbilt University Medical Center
VentureWell
Veterans Prostate Cancer Awareness Inc.
VHL Alliance
Virginia Commonwealth University
wAIHA Warriors
Washington State University
Washington University
West Virginia University
Wiskott-Aldrich Foundation
Yale University
YWHAG Research Foundation

February 20, 2025

The Hon. Susan Collins
Chair
Senate Appropriations Committee
U.S. Senate
Washington, DC 20510

The Hon. Patty Murray
Vice Chair
Senate Appropriations Committee
U.S. Senate
Washington, DC 20510

The Hon. Tom Cole
Chair
House Appropriations Committee
U.S. House of Representatives
Washington, DC 20515

The Hon. Rosa DeLauro
Ranking Member
House Appropriations Committee
U.S. House of Representatives
Washington, DC 20515

Dear Chair Collins, Vice Chair Murray, Chair Cole, and Ranking Member DeLauro,

On behalf of the undersigned organizations, we urge you to prioritize robust funding for the National Institutes of Health (NIH) in the Fiscal Year 2025 appropriations bill and, in that legislation, preserve existing protections against cuts to reimbursement for NIH grantee Facilities and Administrative costs. As a [recent survey](#) commissioned by Research!America shows, the American people overwhelmingly support medical research funding. We hope you can continue to prioritize this engine of health and economic growth in your appropriations bills.

With the March 14 deadline for FY25 appropriations quickly approaching, we ask that you ensure NIH receives at least the \$1.77 billion increase proposed in the bipartisan [Senate FY25 Labor-HHS-Education Appropriations bill](#). A full-year continuing resolution (CR) would plateau NIH funding at a time when scientific opportunity and global competition demand stronger investment. Should a full-year CR be enacted, we urge you to include a \$500 million anomaly for NIH to sustain biomedical research and innovation.

Additionally, we strongly support the continuation of [Section 224](#) of the FY24 Appropriations Act in the final FY25 Appropriations bill since it prohibits changes to NIH Facilities & Administrative cost reimbursements. The Administration's proposed policy to drastically reduce NIH funding by at least \$4 billion would have immediate and harmful consequences—slowing scientific progress, delaying treatments and cures, and weakening the U.S. research ecosystem. NIH funding is a key driver of economic growth, job creation, and medical breakthroughs, and this policy change would hinder our ability to remain globally competitive.

We urge you to finalize FY25 appropriations with strong NIH funding and prevent a sudden and sweeping change in Facilities and Administrative payments. Thank you for your leadership in ensuring continued investment in scientific discovery and innovation.

CC: The Honorable Shelley Moore Capito, Chair, Senate Subcommittee on Labor-HHS-Education
The Honorable Tammy Baldwin, Ranking Member, Senate Subcommittee on Labor-HHS-Education
The Honorable Robert Aderholt, Chair, House Subcommittee on Labor-HHS-Education

Sincerely,

Organizations

Research!America	Alliance to Cure Cavernous Malformation	American Association for the Study of Liver Diseases
#MEAAction	ALS Association	American Association of Colleges of Nursing
#MEAAction Maryland	Alstrom Syndrome International	American Association of Colleges of Pharmacy (AACP)
#MEAAction North Carolina	Alzheimer's Association	American Association of Immunologists
5p- Society	Alzheimer's Impact Movement	American Association of Neuromuscular and Electrodiagnostic Medicine
Academic Data Science Alliance	American Academy of Hospice and Palliative Medicine	American Association of Physicists in Medicine
Academy for Radiology and Biomedical Imaging Research	American Academy of Neurology	American Association of Psychiatric Pharmacists
AcademyHealth	American Academy of Nursing	American Association of Veterinary Medical Colleges
Accessia Health	American Academy of Physical Medicine and Rehabilitation	American Association on Health and Disability
ACT for NIH	American Anthropological Association	American Brain Coalition
Adenoid Cystic Carcinoma Research Foundation	American Association for Anatomy	American Cancer Society Cancer Action Network
AdvaMed	American Association for Cancer Research	American Chronic Pain Association
Advancing Science and Policy (ASAP)	American Association for Dental, Oral, and Craniofacial Research (AADOOR)	American College of Cardiology
AiArthritis	American Association for the Advancement of Science	American College of Clinical Pharmacy
AKARI Foundation		American College of Neuropsychopharmacology
AliveandKick'n		
Alliance for Academic Internal Medicine (AAIM)		
Alliance for Aging Research		
Alliance for Gout Awareness		
Alliance for Headache Disorders Advocacy		

American College of Obstetricians and Gynecologists	American Institute of Biological Sciences	American Society for Gastrointestinal Endoscopy
American College of Osteopathic Internists	American Kidney Fund	American Society for Investigative Pathology
American College of Physicians	American Liver Foundation	American Society for Microbiology
American College of Radiology	American Lung Association	American Society for Pharmacology and Experimental Therapeutics (ASPET)
American College of Rheumatology	American Malacological Society	American Society for Radiation Oncology
American College of Surgeons	American Medical Informatics Association (AMIA)	American Society for Reproductive Medicine
American Council on Education	American Medical Women's Association	American Society of Gene and Cell Therapy (ASGCT)
American Dental Education Association	American Nephrology Nurses Association	American Society of Hematology
American Federation for Aging Research	American Pediatric Society (APS)	American Society of Human Genetics
American Federation for Medical Research	American Pharmacists Association	American Society of Nephrology
American Foundation for Suicide Prevention	American Physiological Society	American Society of Neuroradiology
American Gastroenterological Association	American Phytopathological Society	American Society of Pediatric Nephrology
American Geophysical Union	American Psychological Association Services Inc.	American Society of Transplantation
American Heart Association	American Roentgen Ray Society	American Society of Tropical Medicine and Hygiene
American Industrial Hygiene Association	American Society for Biochemistry and Molecular Biology	American Sociological Association
American Institute for Medical and Biological Engineering (AIMBE)	American Society for Clinical Pharmacology & Therapeutics	

American Statistical Association	Association of American Cancer Institutes	Asthma and Allergy Foundation of America
American Thoracic Society	Association of American Medical Colleges	ASXL Rare Research Endowment Foundation
American Urogynecologic Society	Association of Bioethics Program Directors	Autoimmune Association
Americans for Medical Progress	Association of Biomolecular Resource Facilities	AVAC
Amyloidosis Foundation	Association of Cancer Care Centers	BDSRA Foundation
Aplastic Anemia & MDS International Foundation	Association of Clinical Research Organizations (ACRO)	Bedford VA Research Corporation, Inc.
APS Type 1 Foundation	Association of Diabetes Care & Education Specialists	Beyond Celiac
ARPKD/CHF Alliance	Association of Independent Research Institutions	Bigelow Laboratory for Ocean Sciences
Arthritis Foundation	Association of Maternal & Child Health Programs	BioMojo LLC
Association for Clinical and Translational Science	Association of Minority Health Professions Schools	BioNJ
Association for Clinical Oncology (ASCO)	Association of Population Centers	Biophysical Society
Association for Creatine Deficiencies	Association of Schools and Colleges of Optometry	BioQUEST Curriculum Consortium, Inc.
Association for Molecular Pathology	Association of Schools and Programs of Public Health	Blackstone Health, LLC
Association for Psychological Science	Association of University Anesthesiologists	Bone Health and Osteoporosis Foundation
Association for Women in Science		Boston Children's Hospital
Association of Academic Health Sciences Libraries (AAHSL)		Boston Medical Center Health System
Association of Academic Physiatrists		Brandeis University
Association of Academic Radiology (AAR)		Breakthrough T1D (formerly JDRF)
		BrightFocus Foundation
		Brody School of Medicine at East Carolina University
		California Biomedical Research Association

California Life Sciences	ClearCure Biosciences, Inc.	Council on Undergraduate Research
Cancer Support Community	Clinical Immunology Society	Covalent Solutions, LLC
Carnegie Science	Coalition for Clinical and Translational Science	CSNK2B Foundation
Carolina Music Therapy	Coalition for Life Sciences	Cure Alzheimer's Fund
Cedars-Sinai	Coalition to Cure Calpain 3	Cure CLCN6, Inc.
Celiac Disease Foundation	Coalition to Cure CHD2	Cure CMD
Center for Endometriosis Care	Cold Spring Harbor Laboratory	CURE Epilepsy
Center for Patient Advocacy Leaders (CPALs)	College of the Holy Cross	Cure GM1 Foundation
CEPI U.S.	College on the Problems of Drug Dependence	Cure HHT
CHAMP1 Research Foundation	Columbia University	Cure KCNH1 Foundation
Childhood Arthritis and Rheumatology Research Alliance	COMBINEDBrain	Cure Mucopolidosis
Children's Cancer Cause	Conference of Boston Teaching Hospitals	cureCADASIL
Children's Cardiomyopathy Foundation	Congenital Hyperinsulinism International	Cures Within Reach
Children's Hospital Association	Consortium of Social Science Associations	CureSHANK
Children's Hospital of Philadelphia	Constantiam Biosciences	Cutaneous Lymphoma Foundation
Children's National Hospital	COPD Foundation	Cystic Fibrosis Foundation
Children's Hospital Colorado	Cornell University	Cystic Fibrosis Research Institute
Choose Healthy Life	Council of Medical Specialty Societies	Cystinosis Research Foundation
ChristianaCare	Council of Professional Associations on Federal Statistics	Damon Runyon Cancer Research Foundation
		Dana-Farber Cancer Institute
		Decoding Developmental Epilepsies
		Defeat Multiple System Atrophy Alliance & MSA

United Global Research Consortium	Epilepsies Action Network	Foundation for Sarcoidosis Research
Detroit Parent Network	Epilepsy Foundation of America	Fountain House
Developmental and Epileptic Encephalopathies Project (DEE-P Connections)	EveryLife Foundation for Rare Diseases	Fred Hutchinson Cancer Center
Downstate Health Sciences University	Familial Dysautonomia Foundation	Free ME from Lung Cancer
Dr. R. P. More Youth Power International Organization	FamilieSCN2A Foundation	Friedreich's Ataxia Research Alliance (FARA)
Dravet Syndrome Foundation	Federation of American Societies for Experimental Biology	Friends of FSH Research
Drexel University	Federation of American Societies for Experimental Biology (FASEB)	Friends of NIDA
Duke Health	Federation of Associations in Behavioral and Brain Sciences	Friends of the National Institute of Nursing Research
DYNC1H1 Association	Fight Colorectal Cancer	Future Leaders in Sight (FLIS)
Dysautonomia International	flok Health	GABA-A Alliance
ECAN Esophageal Cancer Action Network	Florence Healthcare	Galactosemia Foundation
Ecological Society of America	FND Hope International	GBS CIDP Foundation International
ECU Health	Focused Ultrasound Foundation	Geneial
Eisai Inc.	FOD Family Support Group	Genetic Alliance
Emily's Entourage	FORCE: Facing Our Risk of Cancer Empowered	Genetics Society of America
Emory University	Foundation Fighting Blindness	Gerontological Society of America
Endocrine Nurses Society	Foundation for Prader-Willi Research	Global Alzheimer's Platform Foundation
Endocrine Society		Global Genes
Entomological Society of America		Global Liver Institute
		GNB1 Advocacy Group, Inc.

GO2 for Cancer	HudsonAlpha Institute for Biotechnology	International Pemphigus and Pemphigoid Foundation
Good Days	Huntington Medical Research Institutes	International SCN8A Alliance
Gout Support Group of America	Hydrocephalus Association	International Society for Environmental Epidemiology, North America Chapter
Grayscale LLC	Hypertrophic Olivary Degeneration Association	International Society for Stem Cell Research
GRIN2B Foundation	IAVI	International Society on Thrombosis and Haemostasis (ISTH)
Hannah's Hope for Giant Axonal Neuropathy Inc	IEEE SA Neuroethics Subcommittee	Interstitial Cystitis Association
Harvard University	Immune Deficiency Foundation	J. Craig Venter Institute
Haystack Project	Infectious Diseases Society of America	J. David Gladstone Institutes
HCU Network America	Inflammatory Breast Cancer Research Foundation	Jane Coffin Childs Memorial Fund for Medical Research
HD Reach	Infusion Access Foundation	Joanna Sophia Foundation
Head for the Cure	International Bipolar Foundation	Johns Hopkins University & Medicine
Health Care Without Harm	International Essential Tremor Foundation	Juju and Friends CLN2 Warrior Foundation
HealthyWomen	International Fibrodysplasia Ossificans Progressiva (FOP) Association	Keck School of Medicine
Heart Failure Society of America	International Foundation for Gastrointestinal Disorders	KidneyCAN
Heart Valve Voice US	International Myeloma Foundation	Kids for Saving Earth
Hepatitis B Foundation		Kids With Heart National Assn for Children's Heart Disorders, Inc.
Hereditary Angioedema Association		KIF1A.ORG
Hereditary Disease Foundation		
Hermansky-Pudlak Syndrome Network		
Hide & Seek Foundation		
HIV Medicine Association		
Hope Charities		
Hope for HIE		
Hope for ULD		

Krishnan Family Foundation	MdDS Balance Disorder Foundation	National Alliance of State Prostate Cancer Coalitions
La Jolla Institute for Immunology	Medical College of Wisconsin	National Alliance on Mental Illness
Lasker Foundation	Medical Library Association	National Alopecia Areata Foundation
LEAD Coalition (Leaders Engaged on Alzheimer's Disease)	Meharry Medical College School of Global Health	National Association for Biomedical Research
Lehigh University	Melanoma Research Foundation	National Association of Hispanic Nurses
Les Turner ALS Foundation	Men's Health Network	National Association of Lesbian Gay Bisexual Transgender Addiction Professionals and Their Allies
Let's Talk UTI, INC	METAvivor Research and Support	National Association of Veterans Research and Education Foundations (NAVREF)
LIVESTRONG	Microbiology and Immunology, Stritch School of Medicine, Loyola Chicago	National Ataxia Foundation
Loma Linda University	Milken Institute School of Public Health at the George Washington University	National Bleeding Disorders Foundation
Loving Loic Foundation	Misra Wellness	National Fabry Disease Foundation
LUNGeivity Foundation	Mission MSA	National Foundation for Ectodermal Dysplasias
Lupus and Allied Diseases Association, Inc.	Mississippi Metabolics Foundation	National Health Council
Lupus Foundation of America	MitoAction	National Hispanic Health Foundation
Lymphatic Education & Research Network	Morehouse School of Medicine	National Infusion Center Association
M-CM Network	Mount Sinai Health System	National Kidney Foundation
Maestro Games SPC	MSUD Family Support Group	
Magee-Womens Research Institute and Foundation	National Alliance for Eye and Vision Research	
March of Dimes		
Marymount University		
Mass General Brigham		
Massachusetts Society for Medical Research		

National Minority Quality Forum	North American Society for Pediatric Gastroenterology, Hepatology and Nutrition	Orthopaedic Research and Education Foundation
National Multiple Sclerosis Society	North American Vascular Biology Organization	Ovarian Cancer Research Alliance
National Organization for Rare Disorders	North Carolina Association for Biomedical Research	Pacific Health Research & Education Institute
National Postdoctoral Association	Northeast Ohio Medical University	Palo Alto Veterans Institute for Research
National Psoriasis Foundation	Northeastern Illinois University	Pancreatic Cancer Action Network (PanCAN)
National Urea Cycle Disorders Foundation	Northeastern University	Patient-Led Research Collaborative
NBIA Disorders Association	Northern California Institute for Research and Education, Inc., NCIRE	Pediatric Endocrinology Nursing Society
NDRI-USA Inc.	Northern Nevada Genetic Counseling	Penn State Health and Penn State College of Medicine
Nebraska Cures	Northwestern University	Pennsylvania Prostate Cancer Coalition
Neev Kolte & Brave Ronil Foundation	Nutrition and Medical Foods Coalition	Pennsylvania Society for Biomedical Research
NephCure	Nyamira County media & Emergency Volunteers Researchers	Personalized Medicine Coalition
NeuroCores	NYU Langone Health	Phelan-McDermid Syndrome Foundation
Neurofibromatosis Michigan	Oakland University	Pheo Para Alliance
Neurotech Network	Oncology Nursing Society	Philadelphia Research & Education Foundation (PREF)
Nevada Cancer Coalition	OncoSpherix, Inc	PINK Concussions
New America's Future of Work and Innovation Economy initiative	Oregon Health & Science University	PKD Foundation
New Jersey Association for Biomedical Research	Organic Acidemia Association	Platelet Disorder Support Association
NF Midwest		
Noah's Hope-Hope4Bridget		

Population Association of America	Rett Syndrome Research Trust	Society for Imaging Informatics in Medicine
Prevent Blindness	Rock CF Foundation	Society for Immunotherapy of Cancer
Project 8p Foundation	Rubinger Associates	Society for Maternal-Fetal Medicine
Project Sleep	Running On Air	Society for Neuroscience
Proteus Syndrome Foundation	RUNX1 Research Program	Society for Pediatric Radiology
PSC Partners Seeking a Cure	Rutgers University	Society for Pediatric Research (SPR)
Psychonomic Society	Rutgers University Medical School	Society for Research in Child Development (SRCD)
Public Responsibility in Medicine and Research (PRIM&R)	Safe Kids Worldwide	Society for the Psychological Study of Social Issues
Pulmonary Fibrosis Foundation	Saint Louis University	Society for Women's Health Research
Pulmonary Hypertension Association	Samtek Inc.	Society of Behavioral Medicine
PXE International	Santa Cruz Strategies LLC	Society of Clinical Research Associates (SOCRA)
QE Philanthropic Advisors	SATB2 Gene Foundation	Society of Environmental Toxicology and Chemistry (SETAC)
Radiological Society of North America	School of Dentistry, University of Utah	Society of Gastroenterology Nurses and Associates, Inc.
Rare Epilepsy Network	Science Policy Advocacy Network	Society of General Internal Medicine
RASopathies Network	Science Policy Initiative at Notre Dame	Society of Gynecologic Oncology
Recurrent Pregnancy Loss Association	Science Policy Network - Detroit	
Redenlab / The University of Melbourne	Shepherd University	
Regenerative Medicine Foundation	Shwachman-Diamond Syndrome Foundation	
Research!America	Sjogren's Foundation	
Restless Legs Syndrome Foundation	Sleep Consortium, Inc.	
	Sleep Research Society	
	Society for Birth Defects Research and Prevention	

Society of Interventional
Radiology

Society of Nuclear
Medicine and Molecular
Imaging

Society of Skeletal
Radiology

Society of Toxicology

Society of Vacuum
Coaters (SVC)

SOGIE Health Equity
Research Collaborative

Solve M.E.

SOUTH SHORE
HOSPITAL

Southern California
Fertility Center

SPIE -the International
Society for Optics and
Photonics

Spina Bifida Association

Spina Bifida Resource

St. Jude Children's
Research Hospital

Stanford University

Staten Island Multiple
Myeloma Support Group

STEMedia Incorporated

Stony Brook University

Susan G. Komen

TB Alliance

TED Community
Organization

Texas Biomedical
Research Institute

Texas Healthcare &
Bioscience Institute

Texas Society for
Biomedical Research

The Ad Hoc Group for
Medical Research

The AIDS Institute

The Alliance for Longevity
Initiatives

The American Society for
Cell Biology

The Association for
Frontotemporal
Degeneration (AFTD)

The Association for
Research in Vision and
Ophthalmology (ARVO)

The Bonnell Foundation:
Living with Cystic Fibrosis

The George Washington
University

The Headache and
Migraine Policy Forum

The Icahn School of
Medicine at Mount Sinai

The Inchstone Project

The Judy Nicholson
Foundation

The LAM Foundation

The LCC Foundation

The Leukemia &
Lymphoma Society

The Louisa Adelynn
Johnson Fund for
Complex Disease

The Lundquist Institute
for Biomedical
Innovation

The Marfan Foundation

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Tyler MacDonald	Vern Schramm, PhD	Victoria Grunberg
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	Veronica Gregory	Victoria Rice
Utsav Gyawali		Victoria Singer
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Vincent McGinty	Wade DeJager	Wenwei Hu
Vincent Silverman	Waheed U. Bajwa	Wesley Tung
Virginia Davis Floyd, MD, MPH	Walt Shotwell	Whitney Lai
Virginia Durik	Walt Tapper	Whitney Neal
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Vivian Taylor	Wayne Faglier	William A. Muller
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Vladislav Friedman	Wendy Braden	William D. Chey, MD
Vlai Ly	Wendy Conlon, MS	William Douglas Evans
Vrinda Desai	Wendy Gunn	William Fuller, MD
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	Wendy McMillan	William Green

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William Witt	Yanille Taveras	Zachary Moore
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Wong Chee Yean	Ying-Xian Pan	Zhengdong Zhang
Xana Howard	Yi-Ping Li	Zhengzhi Xie
	Yong Kim	Zhi Sheng

Zhiping Pang

Zoë Frazier

Zvi Shapiro

Zinzi Bailey, ScD, MSPH

Zorimar Rivera-Nunez

Zipporah M.

Zuhdi E. Abdo, MD



March 3, 2025

The Honorable Shelley Moore Capito
Chair
Appropriations Subcommittee on Labor, Health
and Human Services, Education and Related
Agencies
U.S. Senate
Washington, DC 20510

The Honorable Robert Aderholt
Chair
Appropriations Subcommittee on Labor, Health
and Human Services, Education and Related
Agencies
U.S. House of Representatives
Washington, DC 20515

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

The Honorable Rosa DeLauro
Ranking Member
Appropriations Subcommittee on Labor, Health
and Human Services, Education and Related
Agencies
U.S. House of Representatives
Washington, DC 20515

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

To meet the needs of America's patients, researchers, providers, and health systems, 194 organizations call for the Agency for Healthcare Research and Quality to be fully funded at \$500 million in FY26.

As our nation's goal of having a system that ensures access to high quality and effective healthcare for all is falling far short of its potential, gaining a better understanding of how our healthcare system works and does not work continues to be bipartisan priority. Federally funded health service research grants are how we identify what is not working and create the evidence-based solutions policymakers need to improve health outcomes for everyone. The Agency for Healthcare Research and Quality (AHRQ) is the leading federal agency for funding health services research (HSR) and primary care research (PCR). AHRQ is the bridge between cures and care and ensures that Americans get the best health care at the best value.

As our nation faces multiple health crises, it is more critical than ever to improve our health systems. For example, rural communities are facing complex health challenges with the ongoing closures of rural hospitals and clinics leading to worsening health outcomes for residents. In parallel, the opioid crisis, which has disproportionately impacted rural America, has ravaged American life as overdose deaths are the leading cause of injury-related death in the U.S. In response to these challenges, AHRQ has long identified rural populations as a priority population to support and continues to fund research to improve rural health systems. While policymakers and health systems take dramatic action to respond to existing healthcare challenges, they are doing so without sufficient evidence on its impact on health outcomes, the value of care, and healthcare access. AHRQ-funded projects fill these knowledge gaps.

AHRQ supports research to broaden access to essential services, improve health care quality, reduce costs, advance patient safety, and decrease medical errors. The RAND Corporation released a [report](#) in 2020, as called for by the Consolidated Appropriations Act of 2018, which identified AHRQ as "the only agency that has statutory authorizations to generate HSR and be the home for federal primary care research, and the unique focus of its research portfolio on systems-based outcomes (e.g., making health care safer, higher quality, more accessible, equitable, and affordable) and approaches to implementing



improvement across health care settings and populations in the United States.” AHRQ offers valuable insights on every facet of the health care system. For example, the National Academy of Sciences, Engineering and Medicine 2021 [report](#) on *Implementing High Quality Primary Care* highlighted the value of and need for federal investments in AHRQ through the National Center for Excellence in Primary Care Research.

To deliver better outcomes, we need to be able to differentiate which healthcare interventions work, for whom they work, and how to implement them. For example, the effectiveness of telehealth is diminished if we do not have an evidence-based approach to provide consistent access regardless of who the patient is, and addressing questions like this is where AHRQ has a proven track record. As the lead agency for health services research and primary care research, AHRQ provides the resources that policymakers, health system leaders, medical providers, and patients need to determine the effectiveness of health systems delivery.

While the vast majority of federally funded research focuses on one specific disease or organ system, AHRQ is the only federal agency that funds research on health systems across the nation. The benefits of investing in health services research through AHRQ can be measured in saved lives, better value care, and improved patient outcomes to ultimately make America healthier. For example, implementing of just one AHRQ-funded [study](#) on reducing hospital acquired conditions prevented an estimated 20,500 hospital deaths and saved \$7.7 billion in health care costs from 2014 to 2017. Additional investments in AHRQ are needed to maximize the implementation of research findings across the public health and health care continuum to improve patient care and keep pace with the rapidly evolving and changing health care landscape.

For these reasons, as you draft the Labor, Health and Human Services, Education, and Related Agencies appropriations legislation for fiscal year 2026, the 194 undersigned members of the Friends of AHRQ respectfully **request no less than \$500 million in funding for the Agency for Healthcare and Research and Quality (AHRQ)**. This request reflects an inflation adjustment from FY10 and the demonstrated need to expand and accelerate HSR investments to inform decision-making on the health care system.

AHRQ is the federal vehicle for studying and improving the United States healthcare system, and it needs the resources to meet its mission and this moment. Through this appropriation level, AHRQ will be better able to fund the “last mile” of research from cure to care.

Thank you for your support of AHRQ and health services research. For more information, please contact Josh Caplan at Josh.Caplan@AcademyHealth.org.

Sincerely,

Academic Pediatric Association
AcademyHealth
Accessia Health
Alliance for Academic Internal Medicine (AAIM)
Alliance for Aging Research
American Academy of Allergy, Asthma & Immunology

American Academy of Family Physicians
American Academy of Hospice and Palliative Medicine
American Academy of Nursing
American Academy of Pediatrics
American Academy of Physician Associates
American Association for Dental, Oral, and Craniofacial Research



American Association for Men in Nursing
American Association for Physician Leadership (AAPL)
American Association of Colleges of Nursing
American Association of Colleges of Osteopathic Medicine
American Association of Colleges of Pharmacy (AACP)
American Association of Neuromuscular and Electrodiagnostic Medicine
American Association on Health and Disability
American Board of Medical Specialties
American Brain Coalition
American Chiropractic Association
American College of Clinical Pharmacy
American College of Emergency Physicians
American College of Neuropsychopharmacology
American College of Nurse-Midwives
American College of Obstetricians and Gynecologists
American College of Physicians
American College of Preventive Medicine
American College of Rheumatology
American Epilepsy Society
American Health Information Management Association (AHIMA)
American Heart Association
American Liver Foundation
American Medical Informatics Association (AMIA)
American Nephrology Nurses Association
American Neurological Association
American Nurses Association
American Occupational Therapy Association
American Osteopathic Association
American Pediatric Society
American Physical Therapy Association
American Psychiatric Association
American Psychological Association Services
American Public Health Association
American Society for Nutrition
American Society for Transplantation and Cellular Therapy
American Society of Anesthesiologists
American Society of Clinical Psychopharmacology (ASCP)
American Society of Hematology

American Society of Nephrology
American Society of Pediatric Nephrology
American Speech-Language-Hearing Association
American Statistical Association
American Telemedicine Association
American Thoracic Society
Anesthesia Patient Safety Foundation
Association for Clinical and Translational Science
Association for Diagnostics & Laboratory Medicine
Association for Prevention Teaching and Research
Association for Professionals in Infection Control and Epidemiology (APIC)
Association of American Medical Colleges
Association of Departments of Family Medicine
Association of Family Medicine Residency Directors
Association of Medical School Pediatric Department Chairs
Association of Minority Health Professions Schools
Association of Population Centers
Association of Schools and Programs of Public Health
Association of Women's Health, Obstetric and Neonatal Nurses
ATA Action
Avera
Betsy Lehman Center for Patient Safety
Brigham and Women's Hospital, Division of General Internal Medicine
Brown University
Cedars-Sinai
Children's Hospital Association
Clinical Research Forum
Coalition for Clinical and Translational Science
Coalition for National Trauma Research
Columbia University Irving Medical Center
Comagine Health
Consortium of Social Science Associations
Consumers Advancing Patient Safety
Council of Medical Specialty Societies
Department of Health Policy and Management, School of Public Health, University of Maryland at College Park



Duke Health
ECRI
Emergency Nurses Association
Epilepsy Foundation of America
Evidence-Based Research Network
Federation of Associations in Behavioral and Brain Sciences
Gerontological Society of America
Harvard University
Health Care Systems Research Network
Health Hats
HealthPartners Institute
HealthyWomen
Heart Failure Society of America
Heart Rhythm Advocates
Heart Rhythm Society
Henry Ford Health
HIMSS
Human Services Research Institute (HSRI)
Hydrocephalus Association
Infusion Access Foundation
IPUMS, University of Minnesota
Islamic Civic Engagement Project
Johns Hopkins University & Medicine
Kaiser Permanente
Lakeshore Foundation
Lupus and Allied Diseases Association, Inc.
March of Dimes
Marshfield Clinic Health System
Montgomery County (Maryland) Commission on Aging
Morehouse School of Medicine
Mothers Against Medical Error
Mount Sinai
NADPH
NAPCRG
National Alliance for Eye and Vision Research
National Association of Health Data Organizations (NAHDO)
National Association of Nurse Practitioners in Women's Health
National Association of Pediatric Nurse Practitioners
National Ataxia Foundation
National Black Nurses Association, Inc
National Eczema Association
National Hispanic Health Foundation
National Infusion Center Association

National League for Nursing
National Nurse-Led Care Consortium
National Psoriasis Foundation
National Rural Health Association
NCQA
New York University
Northwestern University
Nurses Organization of Veterans Affairs (NOVA)
NYU Langone Health
Oregon Health & Science University
Pantheon
Patient is Partner
Patient Precision Inc.
Patients for Patient Safety US
Pediatric Policy Council
Penn State Health
Penn State University
Population Association of America
Post-Acute and Long-Term Care Medical Association
Premier Inc.
Prevent Blindness
Project Patient Care
Ready for Change
Research!America
Rice University
RTI International
Schneider Research Associates, LLC
Scientific Knowledge Accelerator Foundation
Sleep Research Society
Society for Healthcare Epidemiology of America
Society for Maternal-Fetal Medicine
Society for Pediatric Research
Society for Public Health Education
Society for Research on Adolescence
Society for Women's Health Research
Society of General Internal Medicine
Society of Hospital Medicine
Society of Teachers of Family Medicine
Spina Bifida Association
Texas Health Resources
The Dartmouth Institute for Health Policy and Clinical Practice
The Larry A. Green Center for the Advancement of Primary Health Care for the Public Good
The Leapfrog Group



The Lundquist Institute for Biomedical
Innovation at Harbor-UCLA Medical Center
The Patient Revolution
The Society of Thoracic Surgeons
The University of North Carolina at Chapel Hill
Tuskegee University College of Veterinary
Medicine
UCLA
UConn Center on Aging
United Ostomy Associations of America
University of Arkansas for Medical Sciences
University of California, San Francisco
University of Colorado Anschutz Medical
Campus
University of Michigan - Institute for Healthcare
Policy & Innovation
University of Oregon
University of Pittsburgh Medical Center
(UPMC)
University of Rochester
University of Utah Health
University of Washington
Vanderbilt University Medical Center
VNS Health
Wake Forest University School of Medicine
Washington State University
Weill Cornell Medicine
Western Washington University

March 5, 2025

VIA ELECTRONIC TRANSMISSION

Dr. Matthew J. Memoli
Acting Director
US National Institutes of Health
9000 Rockville Pike
Bethesda, MD 20892

Dear Dr. Memoli:

We write to express our appreciation for the National Institutes of Health's (NIH) longstanding commitment to funding scientific research that advances medical breakthroughs. NIH's support has been instrumental in fostering innovation, improving patient outcomes, and sustaining the biomedical research enterprise, making the US the global powerhouse in medical innovation. We recognize the importance of ensuring that federal research dollars are used efficiently and effectively to maximize their impact. However, we are deeply concerned about the recently announced policy imposing a 15% cap on indirect cost recovery for NIH grants.¹ Given the far-reaching implications of this change, we respectfully urge NIH to rescind this directive and instead work collaboratively with us, our colleagues, and the US Office of Management and Budget (OMB) to develop a solution that balances transparency, efficiency, and sustainability.

The collateral damage of this policy, if implemented, will be profound and generational, reshaping the future of scientific progress in ways that cannot be easily undone. Beyond its immediate financial strain, the policy introduces significant procedural and structural issues that undermine the integrity of federal research funding. Below, we outline the specific concerns with the supplemental guidance and its broader implications.

Risk Tolerant Ecosystem

A defining strength of the US research enterprise is its risk tolerance—the ability to pursue bold, high-risk, high-reward scientific discoveries that push the boundaries of innovation and our understanding of the human body. This capacity to absorb uncertainty has been the foundation of American leadership in biomedical research and technological advancement, setting the US apart from other nations. Many of the most significant commercial, technological, and biomedical breakthroughs can be traced back to the federally supported research pipeline—one that thrives because of its ability to swing for the fences.

A critical component of NIH's success is its investment in basic research—the study of fundamental biological processes without immediate commercial objectives. These discoveries often lead to pivotal advancements in medicine. For example, research into the immune system's molecular workings laid the foundation for cancer immunotherapy, which harnesses the body's immune system to fight cancer. Such innovations stem from a research pipeline that would not exist without stable federal investment.²

¹ National Institutes of Health (NIH) (2025), NOT-OD-25-068: NIH Implementation of a Uniform 15% Indirect Cost Rate, <https://grants.nih.gov/grants/guide/notice-files/NOT-OD-25-068.html>.

² NIH, Basic research digital media kit, <https://www.nih.gov/news-events/basic-research-digital-media-kit#funding>.

There are around 10,000 known diseases, 7,000 of which are rare, and treatments for around 500 of them. Neurological diseases and disorders have become a major priority for federal investment due to their devastating impact on the US healthcare system and global health. Six of the ten leading causes of death and disability are linked to neurological conditions, with stroke being the nation's leading cause of long-term disability.^{3, 4} The BRAIN Initiative recognized the foundational contributions of neuroscience to potential therapies.⁵ Physicians' progress to groundbreaking discoveries drives commercial innovation, preventive strategies, and evidence-based medical advancements that improve patient outcomes and long-term neurological health.

Funding from private foundations, while valuable, serves as an amplifier. The university research ecosystem is fundamentally built on federal research funding, with indirect cost rates intended to reflect expenses required to sustain groundbreaking scientific work. Appropriate indirect cost recovery is not limited to NIH grants; it is essential across all federal research funding mechanisms, whether through grants, cooperative agreements, or contracts. The necessity of federal support for research infrastructure is not unique to NIH. A parallel example can be found in the US National Aeronautics and Space Administration (NASA), where federally funded research has catalyzed transformative advancements in aerospace technology. The success of SpaceX as a dominant force in commercial spaceflight would have been improbable, if not impossible, without NASA's foundational investments in space exploration, infrastructure, and technology. Just as NIH leverages external partners to advance medical research and develop revolutionary treatments, NASA invests in external research partnerships with appropriate cost recovery to maintain US leadership in space exploration and technology.

The proposed 15% cap on indirect cost recovery would disrupt this well-established research ecosystem, forcing institutions to absorb critical infrastructure costs. No major research university could sustain its operations under this funding model, which would dismantle the very framework that has enabled US institutions to lead in global research and innovation. For researchers engaged in high-impact, transformative science, the financial strain would be untenable, leading many to leave academia for industry positions where they can pursue commercially viable products with fewer financial constraints.

In the broader context of federal spending, the cost of sustaining a strong research enterprise is minimal. However, the consequences of this policy shift will be anything but. Once dismantled, these funding structures will not be easily restored. The very research that drives medical advancements, fuels economic growth, and sustains America's competitive edge will suffer—not because of a lack of talent or opportunity but because of an arbitrary policy that undermines the financial sustainability of research institutions.

Global Competitiveness and National Security

The US remains at the global forefront of life-saving treatment, breakthrough technologies, and state-of-the-art facilities thanks, in part, to sustained NIH funding. The US accounts for over 40% of the global medical technology market, leading in the development and export of advanced medical devices over time with demonstrated growth over the years.^{6, 7} The US maintains most of the world's best-specialized

³ Feigin, V. L., Vos, T., Nichols, E., et al. (2024), Global burden of neurological disorders: A systematic analysis for the Global Burden of Disease Study 2021, *The Lancet Neurology*, [https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(24\)00023-4/fulltext](https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(24)00023-4/fulltext)

⁴ US Centers for Disease Control and Prevention, Stroke facts and statistics, <https://www.cdc.gov/stroke/data-research/facts-stats/index.html>.

⁵ NIH, Blog Post: A look back at the BRAIN Initiative in 2023 and what's coming in 2024. January 31, 2024,

<https://braininitiative.nih.gov/news-events/blog/brain-initiative-alliance-look-back-brain-initiative-2023-and-whats-coming-2024>.

⁶ Advanced Medical Technology Association, Medical device industry facts, <https://www.advamed.org/medical-device-industry-facts/>.

⁷ US Department of Commerce, Medical technologies, <https://www.trade.gov/medical-technologies-0>.

hospitals in oncology, cardiac surgery, neurosurgery, gastroenterology, urology, and other critical fields, attracting patients from around the world and reinforcing its status as the leading destination for medical tourism.^{8, 9} These specialized hospitals are also recipients of NIH funding, supporting multidisciplinary research teams that foster new investigators, physician-scientists, and research assistants who form the backbone of the next generation of medical innovation. Moreover, NIH-funded researchers are recognized on the global stage for paramount discoveries and advancements in the medical field – with more Nobel Prize winners in Physiology or Medicine than any other country.¹⁰

Like the US, many countries have career development and talent recruitment programs to attract and retain researchers in key scientific fields. They offer fellowships, international exchanges, and grant funding to incentivize collaboration not just domestically but also with global partners. However, countries of concern have increased state-sponsored initiatives designed to undermine US research innovation. For example, the Chinese Communist Party (CCP) has aggressively expanded its biomedical research enterprise as a part of the 14th Five-Year Plan for Bioeconomy Development.¹¹ Biomedicine and biosecurity are two of the four major fields with an outline of three powering pathways to success, including biotechnology innovation (i.e., new medicine development, synthetic biology), industrial development (i.e., workforce), and government policies designed to accelerate research output. Their goals are measured in two stages. From 2021 – 2025, the CCP seeks to increase the total scale of its bioeconomy, promote comprehensive strength in biotechnology, and develop industrial integration. In 2022, China surpassed the US in the Nature Index for natural sciences, reflecting its research output and quality.¹² By the end of this year, Chinese universities are expected to produce nearly twice as many PhD graduates in science and technology as their US counterparts.¹³ Moreover, the CCP's expansion strategy is not limited to domestic investments. Since 2008, the CCP has targeted US-funded researchers, institutions, and intellectual property critical to economic and national security. Congressional committees and government agencies have extensively documented these efforts, highlighting cases where NIH-funded research has been replicated or transferred to China for strategic advantage.^{14, 15} In response, Congress has taken bipartisan steps to minimize undue foreign influence, but the risk remains urgent and ongoing.¹⁶

If NIH reduces stable, long-term funding for high-risk, high-reward science, the US research pipeline will weaken, driving researchers to seek opportunities abroad. This policy shift would undermine America's biomedical leadership, erode its workforce competitiveness, and threaten national security, ultimately ceding scientific and technological dominance to global competitors.

⁸ Newsweek, The World's Best Specialized Hospitals 2024, <https://www.newsweek.com/rankings/worlds-best-specialized-hospitals-2024>.

⁹ Medical Tourism Magazine, (2023), What are the best countries for cancer treatment?, <https://www.magazine.medicaltourism.com/article/what-are-the-best-countries-for-cancer-treatment>.

¹⁰ Statista, (2023), Nobel Prize laureates in Physiology or Medicine by nationality, <https://www.statista.com/statistics/262896/nobel-prize-laureates-in-medicine-by-nationality/>.

¹¹ Government of China, (2022), 14th Five-Year Plan for Bioeconomy Development, <https://leap.unep.org/en/countries/cn/national-legislation/14th-five-year-plan-bioeconomy-development>.

¹² Cyranoski, D., (2023), China overtakes United States on key research impact measure, *Nature*, <https://www.nature.com/articles/d41586-023-02159-7>.

¹³ The Economist, (2024), China has become a scientific superpower, <https://www.economist.com/science-and-technology/2024/06/12/china-has-become-a-scientific-superpower>.

¹⁴ US Senate Permanent Subcommittee on Investigations, (2019), China's talent recruitment plans: How China's government is paying scientists inside the United States to transfer US taxpayer-funded research and innovation to China, <https://www.hsgac.senate.gov/wp-content/uploads/imo/media/doc/2019-11-18%20PSI%20Staff%20Report%20-%20China's%20Talent%20Recruitment%20Plans%20Updated2.pdf>.

¹⁵ US Senate Health Education, Labor & Pensions Committee, Full Committee Hearing: Protecting US Biomedical Research: Efforts to Prevent Undue Foreign Influence, Thursday, April 22, 2021, <https://www.help.senate.gov/hearings/protecting-us-biomedical-research-efforts-to-prevent-undue-foreign-influence>.

¹⁶ Consolidated Appropriations Act, 2023, Pub. L. No. 117-328, div. FF, §§ 2311-2315, 136 Stat. 4459 (2022).

Administrative Procedure

Federal agencies must adhere to established procedures when making changes to existing policies. Changes to indirect cost agreements, federal acquisition regulations allow all federal agencies to accept approved rates from cognizant agencies to ensure uniformity in indirect cost application.¹⁷ Agencies must notify the OMB of any deviations, and recipients (or subawardees) may dispute the application of their negotiated rates. Additionally, agencies must publicly disclose their procedures for deviating from negotiated rates and include relevant policies in funding opportunity announcements. With respect to changes in policy, federal agencies are generally required to provide public notice and an opportunity for comment before implementing significant policy changes.¹⁸ If a rule or regulation has a substantial economic impact exceeding \$100 million, agencies must conduct a regulatory impact analysis on various government levels and the private sector and should seek to minimize the burden on affected parties.^{19, 20} Additionally, they must assess how new regulations affect small institutions and ensure that any mandates do not create excessive financial burdens without proper consideration.²¹ Agencies generally do not use guidance documents to impose new binding requirements that were not already established in law or regulation. In addition, they are not subject to these requirements if they clarify existing policies or interpret regulations, offer non-binding recommendations, or state that entities retain discretion to comply. Federal courts ruled that agencies cannot impose substantive requirements through guidance documents without undergoing proper administrative procedures.^{22, 23}

The supplemental guidance circumvents these established administrative procedures, imposing a significant policy shift without public notice, opportunity for comment, or regulatory impact analysis. By issuing a binding directive under the guise of guidance, NIH has effectively enacted a substantive policy change without following federal rulemaking requirements. This lack of procedural transparency deprives research institutions of the opportunity to assess, adapt to, or challenge the policy, creating unnecessary disruption and regulatory uncertainty.

Indirect Cost Policy

NIH has long operated under a predictable and structured grant funding framework, ensuring compliance with federal regulations while fostering trust and collaboration between the federal government and research institutions. In general, institutions receiving federal awards are subject to stringent rules and regulations from the US Office of Management and Budget, the awarding federal agency, and other relevant agencies to ensure financial accountability.²⁴ As such, organizations must adhere to extensive eligibility requirements, be subject to annual audits, and follow federally approved indirect cost structures as negotiated with their cognizant agency.²⁵ Cognizant agencies were established to review, negotiate,

¹⁷ OMB, Indirect (F&A) Costs, 2 C.F.R. § 200.414(c).

¹⁸ Administrative Procedure Act, 5 U.S.C. §§ 551-559, 701-706.

¹⁹ Executive Order No. 12866, 3 C.F.R. 638 (1993), as amended by Executive Order No. 14094, 88 Fed. Reg. 21879 (2023).

²⁰ Unfunded Mandates Reform Act of 1995, 2 U.S.C. §§ 1501-1571.

²¹ Regulatory Flexibility Act, 5 U.S.C. §§ 601-612.

²² *Azar v. Allina Health Services*, 587 US 150 (2019), <https://supreme.justia.com/cases/federal/us/587/150/>.

²³ *Appalachian Power Co. v. EPA*, 208 F.3d 1015 (D.C. Cir. 2000), <https://casetext.com/case/appalachian-power-co-v-epa>.

²⁴ US Office of Management and Budget (OMB), Uniform Guidance, 2 C.F.R. § 200.

²⁵ US Department of Health and Human Services, Final Indirect Cost Rates, 48 C.F.R. § 342.705.

and approve cost allocation plans and indirect cost proposals on behalf of all federal agencies.²⁶ Once approved, the federally approved indirect cost rate is generally accepted across many federal agencies.²⁷

The supplemental guidance would create administrative burdens and insert financial instability in a system designed for transparency and efficiency. This abrupt policy shift disrupts longstanding cost negotiation processes, bypasses cognizant agencies, and imposes unilateral restrictions that conflict with existing federal financial management systems, undermining regulatory continuity and consistency in federal grant policies. Research institutions will have to respond to maintain some recovery costs. First, research institutions would have to completely restructure their institutional budgets and financial planning, which would be an extensive, expensive, and multi-year process. Reclassifying costs and shifting previously covered indirect costs, where feasible, will lead to increased compliance and justification requirements. Ultimately, this creates a more complex grant application and budgeting process NIH has historically sought to streamline.

The supplemental guidance uses a one-size approach using private foundations as an example, but it does not consider varying policies that allow appropriate cost recovery. Private foundations vary in their indirect cost agreements, ranging from allowable indirect, shared, and direct costs to sliding scales to better align funding with the diverse needs of grantees.²⁸ For example, the MacArthur Foundation adopts policy “in recognition of nonprofit organizations having indirect costs that are not directly attributable to the Foundation’s funded work but are necessary to support grant-funded projects or activities.”²⁹ As such, this foundation allows shared project costs to include occupancy, utilities, telephone/internet access, etc. The Robert Wood Johnson Foundation also allows occupancy as well as computing services for project or program staff, grants management or administrative staff, and other administrative costs that are incrementally incurred to support the project or program directly.³⁰ To be eligible, awardees must meet specific reporting requirements and disclosures, including federal tax forms. On sliding scales, the Packard Foundation and the Annie E. Casey Foundation structure their indirect cost rates based on an organization’s annual budget.^{31, 32} By contrast, OMB and the NIH generally classify occupancy costs (i.e., rent, utilities, maintenance, and depreciation) as recoverable through an institution’s indirect cost rate. The NIH does allow occupancy to apply to direct cost, but only if the cost is exclusively attributed to the grant-funded activity, is fieldwork, and meets special environmental conditions required for the research.³³

²⁶ Note: The HHS Division of Cost Allocation Program Support Center serves as the cognizant agency responsible for negotiating and establishing indirect cost rates for various organizations, including state and local governments, colleges and universities, hospitals, and other nonprofit entities. For commercial organizations, the NIH Division of Financial Advisory Services acts as the cognizant federal agency for negotiating indirect cost rates.

²⁷ Note: Fiscal Year 2008, the DoD Appropriations Act (Public Law 110-116) imposed a cap on indirect costs for certain DoD contracts, grants, and cooperative agreements, limiting them to 35% of the total cost. It applied to awards funded by the DoD’s Basic Research appropriations, with report language stated it was to ensure federal funds would be directed toward direct research activities. The cap was specific to that fiscal year and certain funding allocations.

²⁸ Council on Governmental Relations, (2017), Comparing foundations to federal government research support, <https://www.cogr.edu/sites/default/files/6.30.17%20Comparing%20Foundations%20to%20Federal%20Government%20Research%20Support.pdf>.

²⁹ MacArthur Foundation, Cost-sharing and in-kind contribution policy, <https://www.macfound.org/about/our-policies/indirect-cost-policy/>.

³⁰ Robert Wood Johnson Foundation, Indirect cost rate policy, https://www.rwjf.org/content/granteeresources/legal-and-policy/Indirect_Cost_Rate.html.

³¹ David & Lucile Packard Foundation (2024), CFI Open Call FAQ, <https://www.packard.org/wp-content/uploads/2024/03/CFI-Open-Call-FAQ-2.pdf>.

³² Annie E. Casey Foundation, (2023), The Casey Foundation’s journey toward equitable grant making, <https://www.aecf.org/blog/the-casey-foundations-journey-toward-equitable-grant-making>.

³³ National Institutes of Health, (2023), NIH Grants Policy Statement, <https://grants.nih.gov/grants/policy/nihgps/nihgps.pdf>.

Assessing private foundations' indirect cost policies requires a comprehensive review of their full funding guidelines rather than isolating a single aspect. The supplemental guidance does not consider their guidelines' broader financial structure, eligibility requirements, and allowable expenses, thus presenting an incomplete picture. Therefore, making direct comparisons to federal funding policies is inappropriate without a thorough evaluation of all contributing factors.

In addition, the supplement guidance unequally burdens institutions with fewer alternative funding sources. Larger research institutions with private endowments, unrestricted funding, or industry partnerships may be able to absorb the funding gap. Smaller institutions and community-based research centers lack financial flexibility.

Cost Sharing Policy

Similar to indirect cost guidelines, private foundations often have specific policies regarding cost-sharing and in-kind contributions to ensure the effective use of their funds and alignment with their philanthropic objectives. In fact, many recognize this and have placed it in their guidelines. The Gates Foundation, for example, has stated in its historical guidelines that it does not match indirect cost rates approved by federal cognizant agencies and recognizes that “applicants may need to engage in cost-sharing between projects, tap into unrestricted funds, or conduct other fundraising to cover operations costs.”³⁴

By contrast, federal research funding policies generally prohibit cost-sharing and in-kind contributions. The OMB has a policy that federal agencies cannot require cost-sharing unless it is explicitly mandated by law or regulation or outlined in a specific funding announcement. If an institution voluntarily includes cost-sharing in a proposal, it must not be used as a factor in funding decisions. This is to ensure that awards are based on scientific merit and project feasibility rather than an institution's financial capacity. When cost-sharing is included, it must be verifiable in institutional records, necessary for achieving project objectives, and allowable under federal cost principles. Additionally, federal agencies are required to apply these rules consistently, ensuring uniform treatment across all applicants. In-kind contributions, such as donated equipment or waived indirect costs, can only count toward cost-sharing obligations if they are explicitly approved, documented, and properly valued. These regulations exist to prevent funding inequities, reduce administrative burdens, and promote transparency, ensuring that institutions with greater financial resources do not gain an unfair advantage over those reliant solely on federal support.³⁵ Institutions' abilities to supplement federal support with private resources can be highly variable. This policy aims to ensure transparency and a level playing field in the distribution of federal grants by ensuring they are based on scientific merit and project feasibility rather than an institution's ability to contribute additional resources.

The supplemental guidance does not consider the varying cost-sharing policies between private foundations and federal government requirements and the reasoning that allows or prohibits its use.

Clinical Studies

Clinical studies are the backbone of medical advancements that offer patients access to cutting-edge, life-saving, and quality-of-life-improving therapies. In fiscal year 2023, NIH allocated \$34.9 billion of its \$47.7 billion budget to competing and non-competing grant awards. This funding supported 58,951

³⁴ Bill & Melinda Gates Foundation (2015). Indirect Cost Policy, https://docs.gatesfoundation.org/documents/historical_indirect_cost_policy.pdf.

³⁵ OMB, Cost sharing or matching, 2 C.F.R. § 200.306.

extramural grants across 2,743 institutions, including universities, hospitals, and research organizations, many of which conduct human and animal clinical trials to advance medical innovation.³⁶

Conducting clinical trials is resource-intensive, with costs extending far beyond patient care and treatment. While much of the funding is allocated to specific research activities—such as data collection, drug administration, and patient monitoring—institutions must also cover regulatory compliance, infrastructure, and administrative expenses that support multiple projects.^{37, 38} One of the most significant financial burdens is regulatory compliance and oversight, which requires dedicated staff, legal review, extensive documentation, and ongoing safety monitoring to meet federal standards for human research. Additionally, maintaining research infrastructure—including specialized laboratory facilities, biostatistical support, and IT systems for secure data storage and patient record management—represents a significant, ongoing expense essential to trial execution. Private foundations benefit from this federal and state regulatory structure.

While these resources are shared across multiple projects, they remain essential for any trial to function. A 15% cap on indirect costs creates a financial gap that disproportionately affects the institutions conducting trials, particularly those without unrestricted funding sources to absorb administrative and infrastructure expenses.

Conclusion

As physicians, we are committed to finding treatments and cures. While we recognize the importance of directing more funding toward direct research costs, this policy carries unintended consequences that threaten the sustainability of US biomedical research. Thank you for considering these concerns. If you have any questions or would like to follow up, please contact Dr. Alex Khalessi, the AANS and CNS Washington Committee Chair, at akhalessi@health.ucsd.edu, and Charlotte Pineda, the AANS and CNS Vice President of Health Policy and Advocacy, at cpineda@neurosurgery.org. We look forward to collaborating with you and other federal agencies to advance solutions that ensure transparency, fairness, and our continued excellence on the global stage.

Respectfully submitted,



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³⁶ NIH, FY 2024 by the numbers: Extramural grant investments in research, February 21, 2024, <https://nexus.od.nih.gov/all/2024/02/21/fy-2023-by-the-numbers-extramural-grant-investments-in-research/>.

³⁷ HHS, Institutional Review Board (IRB) approval process, <https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/institutional-review-boards/index.html>.

³⁸ US Food and Drug Administration, Good Clinical Practice (GCP) standards, <https://www.fda.gov/regulatory-information/search-fda-guidance-documents/e6-r2-good-clinical-practice-integrated-addendum-ich-e6r1>.



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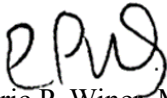
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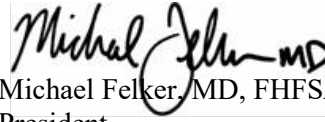
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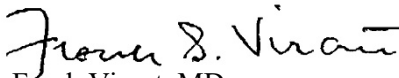
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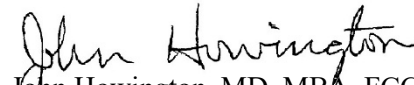
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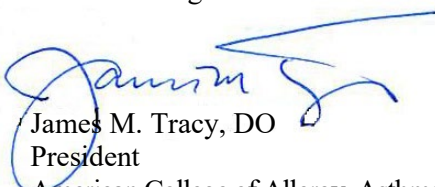
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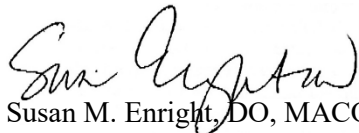
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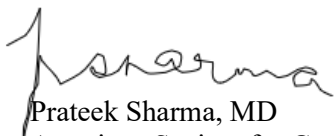
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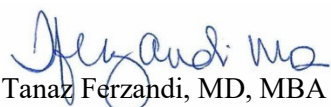
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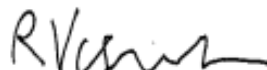
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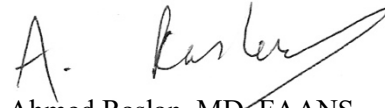
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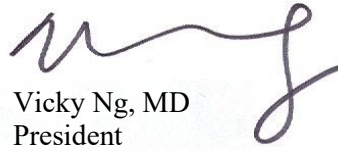
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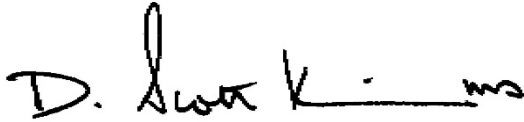
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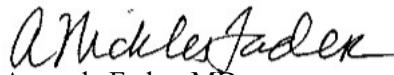
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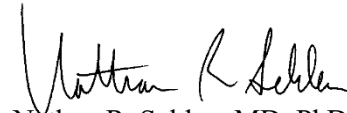
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Professional Organization

Cc: The Honorable Russell Vought, Director, US Office of Management and Budget
The Honorable Susan Collins, US Senator
The Honorable Patty Murray, US Senator
The Honorable Tom Cole, US Representative
The Honorable Rosa DeLauro, US Representative



THE AD HOC GROUP FOR MEDICAL RESEARCH

The Ad Hoc Group Fiscal Year 2026 Recommendation

The 510 undersigned members of the Ad Hoc Group for Medical Research, which includes organizations representing patients, scientists, health professionals, research and academic institutions, educators, and industry, recommends at least **\$51.303 billion for the National Institutes of Health (NIH)** for fiscal year (FY) 2026, in addition to support for the Advanced Research Projects Agency for Health, which would represent a \$4.222 billion or 9.0% increase over the final FY 2025 funding level.

Robust support for medical research makes Americans healthier. Patients across the country -- from urban centers to rural communities -- benefit from medical research supported by the NIH, which serves as the **foundation for nearly every preventive intervention, diagnostic, treatment, and cure in practice today**. Each year, more than 300,000 researchers across labs and other settings in **nearly every congressional district nationwide^{i,ii}** conduct research on the most promising strategies to promote patient well-being and overcome existing and emerging health threats, including cancer, Alzheimer's disease and related dementias, diabetes, Parkinson's, chronic health conditions, and the full range of other diagnoses that patients, families, and communities face every day. Underfunding NIH will slow the pace of scientific discovery as does imposing other problematic disruptions on the agency, placing the health of patients and communities at increased risk.

In addition to the health benefits to patients that medical research promotes, the federal investment in this lifesaving work also has a **multiplier effect in local and regional economies**, spurs new industries, enhances the **U.S.'s global competitiveness**, promotes our **national security**, establishes viable career paths for the **next generation of scientists**, and generates additional **high-quality jobs in communities nationwide**.

As Congress considers funding for the upcoming fiscal year, we note that meaningful annual funding growth for **NIH has been a steadfast bipartisan national priority over the last decade and beyond**. In a time where China and our other global competitors continue to increase investments in medical research and scientific talent, it is crucial that the United States maintains its leadership on the global stage to deliver breakthrough advances for patients and economic growth for communities across the country.

We urge lawmakers to continue to support patients, discovery, and economic growth, to ensure a funding allocation for the Labor-HHS Subcommittee that allows for the necessary investment in NIH and other agencies that promotes the health and well-being of all Americans, and to work expeditiously to complete FY 2026 appropriations in a timely manner. The health of our nation and millions of patients depends on it.

510 Signatories as of April 7, 2025

Academic Consortium for Integrative Medicine and Health

Academic Pediatric Association

Academic Consortium for Integrative Medicine and Health
Academic Pediatric Association
Academy for Radiology and Biomedical Imaging Research
AcademyHealth
Accessia Health
ACMCRN Arachnoiditis & Chronic Meningitis Collaborative Research Network
ACT for NIH
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American Association of Immunologists
American Association of Neuromuscular & Electrodiagnostic Medicine
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American College of Clinical Pharmacy
American College of Neuropsychopharmacology
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American College of Radiology
American College of Rheumatology
American College of Surgeons
American Council on Education

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American Federation for Aging Research
American Federation of Medical Research
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Barth Syndrome Foundation
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Boston University
Breakthrough T1D (formerly JDRF)
Broad Institute
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Case Western Reserve University School of Medicine
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Child Neurology Foundation
Childhood Arthritis and Rheumatology Research Alliance
Children's Healthcare of Atlanta
Children's Hospital Association
Children's Hospital Colorado
Children's Hospital of Philadelphia
Children's Mercy Kansas City
Choose Healthy Life
Chris "CJ" Johnson Foundation Inc
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Cleveland Clinic
Clinical Immunology Society (CIS)
Clinical Research Forum

Coalition for Clinical and Translational Science
Coalition for Pediatric Medical Research
Coalition of Skin Diseases
Coalition to Cure CHD2
College on Problems of Drug Dependence
Colorado State University
Columbia University
Conference of Boston Teaching Hospitals
Congenital Adrenal hyperplasia Research, Education & Support Foundation (DBA: CARES Foundation)
Congenital Hyperinsulinism International
Consortium of Social Science Associations
Cooley's Anemia Foundation
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Council on Social Work Education
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Dravet Syndrome Foundation
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Fabry Support & Information Group
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Fight Colorectal Cancer
Flux: The Society for Developmental Cognitive Neuroscience
FORCE: Facing Our Risk of Cancer Empowered
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Hope for Stomach Cancer
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KPTN Alliance
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Le Bonheur Children's Hospital
LEAD Coalition (Leaders Engaged on Alzheimer's Disease)
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National Ataxia Foundation
National Bleeding Disorders Foundation
National Eczema Association
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National Headache Foundation
National Health Council
National Kidney Foundation
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Postdoctoral Association
National Scleroderma Foundation
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NBIA Disorders Association
NCATS Alliance
Necrotizing Enterocolitis (NEC) Society
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North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
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Oncology Nursing Society
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Prostate Cancer Foundation
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Pulmonary Hypertension Association
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Rare Epilepsy Network (REN) Coordinating Committee
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Restless Legs Syndrome Foundation
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Society for Investigative Dermatology
Society for Maternal-Fetal Medicine
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Society for Reproductive Investigation
Society for Research in Child Development (SRCD)
Society for Vascular Surgery
Society for Women's Health Research
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Society of Behavioral Medicine
Society of Breast Imaging
Society of Clinical Psychology, Division 12 of APA
Society of Directors of Research in Medical Education
Society of Experimental Psychology
Society of General Internal Medicine

Society of Gynecologic Oncology
Society of Interventional Radiology
Society of Nuclear Medicine and Molecular Imaging
Society of Radiologist in Ultrasound
Society of Skeletal Radiology
Society of Teachers of Family Medicine
Society of Toxicology
Society of University Surgeons
St. Baldrick's Foundation
St. Jude Children's Research Hospital
Stanford University
Star Legacy Foundation
Stickler Involved People
StopAfib.org
STXBP1 Foundation
Susan G. Komen
Temple University
Texas A&M University Health Science Center
The American Society for Cell Biology
The American Society of Radiologic Technologists
The Association for Frontotemporal Degeneration
The Association for Research in Vision and Ophthalmology (ARVO)
The Cerebral Palsy Research Network
The Coalition Against Pediatric Pain
The FamilieSCN2A Foundation
The Fibroid Foundation
The Judy Nicholson Kidney Cancer Foundation
The LCC Foundation
The Leukemia & Lymphoma Society
The Louisa Adelynn Johnson Fund for Complex Disease
The Lundquist Institute
The Marfan Foundation
The Michael J. Fox Foundation for Parkinson's Research
The Myalgic Encephalomyelitis Action Network (MEAction)
The National Pancreas Foundation
The Ohio State University Wexner Medical Center
The Rory Belle Foundation
The School of Theoretical Modeling
The STARR Coalition
The University of Houston
The University of North Carolina at Chapel Hill
The University of Texas Medical Branch at Galveston (UTMB)
Tigerlily Foundation
Triage Cancer
TSC Alliance
Tufts University
Tulane University School of Medicine
Tuskegee University College of Veterinary Medicine
UC San Diego Health Sciences
UL Research Institutes

UMass Chan Medical School
Unique (Rare Chromosome and Gene Disorder Support Group)
Unite 2 Fight Paralysis
United for Medical Research
United MSD Foundation
University at Buffalo
University at Buffalo Jacobs School of Medicine and Biomedical Sciences
University Health Partners of Hawaii
University of Alabama at Birmingham
University of California System
University of California, Irvine
University of California, San Francisco
University of Chicago Medical Center
University of Cincinnati
University of Colorado
University of Colorado Anschutz Medical Campus
University of Colorado Boulder
University of Colorado Colorado Springs
University of Colorado Denver
University of Illinois College of Medicine
University of Iowa
University of Maryland, Baltimore
University of Miami Miller School of Medicine
University of Michigan
University of Minnesota Medical School
University of Mississippi Medical Center
University of Nevada Las Vegas (UNLV)
University of Nevada, Reno School of Medicine
University of New Mexico
University of Oregon
University of Pennsylvania
University of Pittsburgh
University of Puerto Rico School of Medicine
University of Rochester
University of Utah Health
University of Virginia
University of Wisconsin - Madison
UsAgainstAlzheimer's
Usher 1F Collaborative
Usher Syndrome Coalition
Usher Syndrome Society
UTRGV School of Medicine
UVA Health
v-ATPase Alliance
Vandalia Health
Vanderbilt University
Vanderbilt University Medical Center
VentureWell
VHL Alliance
Virginia Tech

Ad Hoc Group for Medical Research
FY 2026 Recommendation
P. 12

Vision Sciences Society
wAIHA Warriors
Washington State University
Washington University in St. Louis
Wayne State University
West Virginia University
Western Michigan University Homer Stryker M.D. School of Medicine
Wilson Disease Association
Wiskott-Aldrich Foundation
World Molecular Imaging Society
Yale University

ⁱ National Institutes of Health. Impact of NIH Research; Direct Economic Contributions.
<https://www.nih.gov/about-nih/what-we-do/impact-nih-research/serving-society/direct-economic-contributions>.
Accessed February 5, 2025.

ⁱⁱ Federation of American Societies for Experimental Biology. Federal Research Funding Data.
<https://www.faseb.org/science-policy-and-advocacy/federal-funding-data>.
Accessed March 7, 2025.

April 30, 2025

The Honorable Robert F. Kennedy Jr.
Secretary
Department of Health and Human Services
200 Independence Avenue SW
Washington, D.C. 20201

Dear Secretary Kennedy:

We are writing with profound concern regarding the recent reorganization and Reductions in Force (RIF) within federal health agencies, and specifically their impact on the staff and offices that manage the systemic lupus erythematosus (lupus) programs at the Centers for Disease Control and Prevention (CDC Lupus Program) and the National Lupus Outreach and Clinical Trial Education Program at the HHS Office of Minority Health (OMH Lupus Program). These are the only lupus-specific programs at the Department of Health and Human Services (HHS) and are vital to the fight against lupus, an incurable chronic autoimmune disease that can be fatal. Lupus impacts the lives of an estimated 1.5 million Americans, including children, and is the 10th leading cause of death in women ages 15-24.

The CDC and OMH Lupus Programs fill critical gaps in lupus research, awareness, and care. They improve our understanding of lupus in the United States, the incidence and prevalence of the disease and its impact on children. By raising awareness of the signs and symptoms of lupus among primary care and emergency department physicians, as well as patients, they help reduce the time to diagnosis and ensure people with lupus receive prompt access to care, lowering the risk of severe complications. These initiatives also empower individuals with lupus to take greater control of their own health care through innovative self-management programs. At the same time, they enhance efficiency and effectiveness of lupus clinical trials, enabling physicians to identify improved treatments and deliver more personalized care. In short, these programs improve health outcomes, reduce costs, and save lives. Yet, the future of these programs is at risk because the staff who manage them have been subject to RIFs and the offices in which they are housed may no longer exist.

Earlier this year, President Trump created the Make America Healthy Again (MAHA) Commission with goals that include improving our understanding of chronic diseases, lowering the rates at which they occur in the United States and ending childhood chronic disease. When announcing the

Commission, the President highlighted autoimmune diseases, particularly their prevalence in the U.S, and among children, as examples of the need to address the growing health care crisis in America. The CDC and OMH Lupus Programs share many of the same goals that were articulated by the President.

These programs were created by Congress to prioritize the nation's fight against lupus, a chronic autoimmune disease in which the body's immune system attacks healthy tissues and organs, causing pain and inflammation. The disease can impact multiple parts of the body, including the skin, joints, kidneys, heart, lungs, and brain, and can be fatal. Thanks to research supported by the CDC Lupus Program, we know that the disease disproportionately impacts women and that women of color are two to three times more likely to develop the disease. We also know that lupus can strike in childhood, often leading to more severe disease, worse outcomes, and higher mortality. Because of this, the CDC's Lupus Program supports projects specifically focused on childhood lupus and improving our understanding of the disease in children, which can lead to new and improved care strategies that support better outcomes in childhood, and sustained health as they enter adulthood.

The CDC Lupus Program has played an instrumental role in the development of additional strategies to combat the disease, including awareness campaigns and self-management programs designed to improve the time to diagnosis and self-care which also can improve outcomes and reduce costs. The National Resource Center on Lupus, created in part through the CDC's Lupus Program, is among the most important tools available to people living with lupus, their families, caregivers, and health care providers, as well as those yet to be diagnosed who are experiencing the symptoms of lupus. The CDC Lupus Program has also supported the development of self-management programs that empower people with lupus to take an active role in their care. These tools help improve treatment adherence and promote healthy lifestyle choices – such as better sleep, diet and nutrition. They also help individuals manage stress, cope with symptoms, and collaborate effectively with their health care team.

The work of the CDC Lupus Program to understand the burden of lupus in the U.S. and to improve care for people living with lupus today goes hand-in-hand with the work of the OMH, which is focused on improving the development of new treatment options and ensuring that those treatments are safe and effective for everyone living with lupus. The OMH Lupus Program was established by Congress to increase participation in lupus research and clinical trials and ensure trials are representative of the lupus population. Lack of representation in research of those most significantly impacted by the disease is one of the most important barriers to advancing lupus care. The OMH Lupus program has developed model action plans to overcome this barrier and is currently implementing those action plans in programs across the country. The OMH Lupus Program plays a critical role in improving lupus research, making it more efficient and more

effective. Most important, by improving participation in lupus research, the OMH Lupus Program provides the medical community, commercial insurers, Medicare, and Medicaid with a better understanding of which treatments are most effective in which patients, enabling them to adapt treatment and coverage decisions to meet the needs of each person living with lupus. Since the OMH Lupus Program was established, three new FDA approved treatments are now available for lupus. Those treatments, in combination with programs supported by the CDC that raise awareness of lupus and help patients manage their disease have led to new ways of treating lupus and afforded lupus patients a level of care only dreamed about just 10 years ago.

In these ways, the CDC and OMH Lupus Programs are essential components of the country's efforts to fight chronic disease and, because lupus is considered a prototypical autoimmune disease, these programs can serve as a model for improving outcomes in many other autoimmune diseases. These are wise investments that improve the health of all Americans living with lupus. We urge HHS to preserve the CDC and OMH Lupus Programs and not walk away from the tremendous progress that has been made. We stand ready to work with you to continue to improve how lupus is treated and to make a difference in the lives of all Americans living with this disease.

We urge you to preserve these important programs, which are the only ones at HHS focused on lupus, and respectfully request that you address the following questions:

CDC Lupus Program

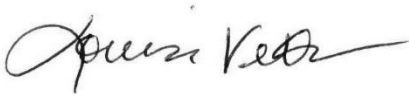
- Will the work conducted and supported by the CDC Lupus Program be shifted to other offices within CDC or to other HHS agencies, such as the new Administration for a Healthy America (AHA)?
- How will the recent staffing changes impact the CDC Lupus Program, and will current or new HHS staff be assigned to manage the program?
- Who are the CDC or HHS points of contact for the lupus community, including for existing grant recipients and those with cooperative agreements, and who at HHS should grant recipients contact with questions regarding progress reports and budget, programmatic and personnel changes?
- There was a Notice of Funding Opportunity (NOFO) forecast for "CDC-RFA-DP-25-0016 Developing and Disseminating Strategies to Build Sustainable Lupus Awareness, Knowledge, Skills, and Partnerships Department of Health and Human Services Centers for Disease Control – NCCDPHP" with an estimated posting date of March 3, 2025. Does the CDC or HHS still plan to issue this opportunity or another opportunity tied to lupus?

OMH Lupus Program

- With the reorganization of the Office of the Assistant Secretary for Health, including the OMH, will the work conducted and supported by the OMH Lupus Program be shifted to the new Administration for a Healthy America (AHA) or another HHS office or agency?
- How will the recent staffing changes impact the OMH Lupus Program, and will current or new HHS or AHA staff be assigned to manage the program?
- Who are the HHS points of contact for existing OMH Lupus Program grant recipients?
- Who at HHS should existing grant recipients contact with questions regarding progress and budget, scope and personnel changes?

Thank you for your consideration of our concerns and questions. Please contact Pat Wildman (wildman@lupus.org) and Adam Cooper (ACooper@rheumatology.org) if you have any questions or for additional information.

Sincerely,



Louise Vetter
President & Chief Executive Officer
Lupus Foundation of America



Carol A. Langford, MD, MHS
President
American College of Rheumatology

May 5, 2025

The Honorable Robert F. Kennedy, Jr.
Secretary
Department of Health and Human Services
2000 Independence Avenue SW
Washington, D.C 20201

Dear Secretary Kennedy,

The American College of Rheumatology (ACR), which serves nearly 10,000 members, rheumatologists and rheumatology interprofessional care team members and the Rheumatology Research Foundation (RRF), write to share guidance during the reorganization of the National Institutes of Health as a part of the broader restructuring of the Department of Health and Human Services. The ACR has had the privilege of working closely with several NIH Institutes and appreciates the shared scientific partnerships fostered through advancements in rheumatic, musculoskeletal, and autoimmune disease research. On behalf of ACR membership, **we write in support of the crucial research and program conducted by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) to address the impacts of chronic conditions and to express concern with the future of NIAMS should it be consolidated into another division**, particularly how the consolidation will affect the essential foundations like rheumatology specific activities conducted under the institute.

Rheumatologists are experts in the diagnosis and treatment of complex autoimmune and musculoskeletal conditions, including rheumatoid arthritis, psoriatic arthritis, osteoarthritis, juvenile arthritis, vasculitis, systemic lupus erythematosus, lupus nephritis, and multiple other debilitating diseases that require ongoing care. Among the chronic diseases that rheumatologists specialize in, arthritis stands out to the degree that it afflicts the American people. As the leading cause of disability in the United States, arthritis affects over 58 million (or 1 in 4) adults according to the CDC. However, a recent study suggests this number could be as high as 91 million (1 in 3). Clinical research programs at NIAMS research and combat the leading cause of disability in the United States.

Rheumatic diseases accumulate \$140 billion in medical costs each year, with an additional estimated \$164 billion in lost wages and productivity when degenerative conditions like osteoarthritis are included. The combined \$304 billion cost of rheumatic diseases is greater than the cost of cancer annually in the United States. Basic, translational, and clinical rheumatology research by programs like NIAMS develops treatments that prevent or mitigate disease progression, improve patient outcomes, and reduce the need for costly surgical interventions or procedures. Investing in this chronic care research allows for more opportunities for active and productive lives for patients and less costly healthcare interventions.

There are an estimated 300,000 children in the U.S. with juvenile arthritis who require specialized care from a pediatric rheumatologist. Earlier this year, President Trump created the Make America Healthy Again (MAHA) Commission with the task of improving our understanding of chronic disease, lowering the rates at which they occur, and preventing

childhood chronic disease. When announcing the Commission, the President highlighted the prevalence of autoimmune diseases among children as an example of the need to address the growing health care crisis in America. NIAMS has a significant role to play in combating juvenile rheumatic disease by supporting a dedicated pediatric rheumatology clinic and fellowship training program within the NIH. The ACR and NIAMS are aligned with the president's goal to mitigate childhood chronic disease.

To this end, the ACR supports NIH and HHS preserving NIAMS programs specific to rheumatic and musculoskeletal disease research, including:

- **The Accelerating Medicines Partnership Autoimmune and Immune-Mediated Diseases (AMP IM) program** to continue research on shared mechanisms of autoimmune and immune mediated diseases, particularly the cellular and molecular interactions that contribute to inflammation. This public-private partnership drives innovation and discoveries for some of the most debilitating rheumatic diseases such as lupus and arthritis.
- **The NIAMS Pain Research Program** to study gaps in knowledge regarding pain mechanisms in the body, biomarkers, and treatment options to prevent or alleviate pain. As many of the diseases under the NIAMS umbrella, including arthritis, cause pain, disability or disfigurement, this program meaningfully improves patient health and quality of life.
- **Restoring Joint Health and Function to Reduce Pain Consortium (RE-JOIN)** to study how sensory neurons with pain receptors connect to the joints and surrounding tissue. Understanding of the distribution of nerves in joint tissue will allow for advanced pain relief for arthritis patients. Project REJOIN is part of the larger NIH HEAL initiative, in which NIAMS plays a key role.
- **Adult and pediatric rheumatology fellowship programs**, both ACGME accredited, train the next generation of academic rheumatology leaders while conducting patient-based clinical trials.

Proposed reorganizations could combine NIAMS with other divisions like the National Heart, Lung, and Blood Institute (NHLBI), and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). While the ACR understands that the current NIH structure of organ-system specific research does not fully reflect contemporary understanding of the human body as an interconnected system – NIAMS research as structured is currently able to focus on the wholistic elements of human mobility and function by seeking to understand the causes, treatments, and prevention of the diseases affecting the bones, joints, muscles, skin and connective tissues.

The ACR is concerned that consolidation of NIAMS with other programs may negatively impact equity in funding distribution by crowding available resources, thus posing the risk of significant reduction in the rheumatology specific research needed to support millions of Americans living with chronic rheumatic disease.

Preserving the fundamental mission of NIAMS to support research into the causes, treatment, and prevention of arthritis, musculoskeletal and skin diseases; the training of basic and clinical

scientists to carry out this research; and the dissemination of information to further research progress in these diseases is paramount. We recognize the need to review the NIH's structure and strategic direction to determine changes to enhance efficiency and ensure future success. However, it is imperative that in structural review, essential elements of NIAMS role in the administration's mission to address chronic disease is not lost.

To this end, the ACR respectfully requests that you address the following questions in reorganization:

- How will reorganization ensure proper attention and allocation of resources to autoimmune disease research including arthritis and lupus?
- How will the work conducted and supported by NIAMS be embedded in any new institute, or within other HHS agencies?
- Given recent staffing changes at HHS, will current or new HHS staff be assigned to manage autoimmune, musculoskeletal and skin disease research within any proposed new institute which NIAMS will be a part?
- Who are NIH or HHS points of contact for researchers, including existing grant recipients and those with cooperative agreements, and who should grant recipients contact with questions regarding progress reports, budget, and programmatic changes?

Thank you for considering our input during this reorganization. The ACR looks forward to partnering with the NIH and HHS as new structures for the institutes within these organizations are considered. Please contact Lennie McDaniel, JD, Head of the ACR's DC Office at LMcDaniel@rheumatology.org should you have any questions or need additional information from the ACR or its membership.

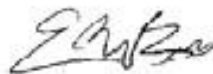
Sincerely,



Christina Downey, MD
Chair, Government Affairs Committee
American College of Rheumatology



Linda Hiraki, MD, FRCPC, ScD
Chair, Committee on Research
American College of Rheumatology



Edward Behrens, MD
Chair, Scientific Advisory Council
Rheumatology Research Foundation

May 8, 2025

The Honorable Robert Aderholt
Chair
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
House Appropriations Committee
U.S. House of Representatives
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
House Appropriations Committee
U.S. House of Representatives
Washington, DC 20515

The Honorable Shelley Moore Capito
Chair
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Senate Appropriations Committee
United States Senate
Washington, DC 20510

The Honorable Tammy Baldwin
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Senate Appropriations Committee
United States Senate
Washington, DC 20510

Dear Chair Aderholt, Ranking Member DeLauro, Chair Capito, Ranking Member Baldwin, and
Members of the Appropriations Committees,

Thank you for your leadership in making important federal funding decisions related to medical research. The 36 undersigned organizations are stakeholders of the research led by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) within the National Institutes of Health (NIH). **We write to request that you include \$747 million for NIAMS in the fiscal year 2026 Labor, Health and Human Services, Education, and Related Agencies appropriations bills, consistent with the Ad Hoc recommendation of a 9% increase for the overall NIH Budget.**

The NIAMS leads the federal effort on research into the causes, incidence, treatment and prevention of diseases and disorders of the bones, joints, muscle, skin and connective tissues. It touches the most fundamental aspects of human mobility and function. These diseases and disorders are costly, chronic, debilitating and common and impact the lives of millions of Americans, affecting nearly every household in the United States.

Current initiatives of NIAMS include:

- **NAIMS role in the Accelerating Medicines Partnership Autoimmune and Immune-Mediated Diseases (AMP AIM) program** is a prime example of public-private partnerships driving innovation. The program looks at shared mechanisms of autoimmune and immune mediated diseases, particularly the cellular and molecular interactions that lead to inflammation and can lead to discoveries for some of the most debilitating and life-altering diseases such as lupus and arthritis.
- NIAMS is leading the **NIH Back Pain Consortium Research Project (NIH BACPAC)**. Lower back pain is the leading cause of disability in the U.S. and

contributes to opioid use. This initiative convenes patients, providers, and researchers to study back pain and develop personalized treatment plans.

In addition, NIAMS' robust external engagement program ensures that supported research is patient centered and meets the needs of stakeholder communities. Stakeholders of the NIAMS research portfolio offer the following observations:

- “Research conducted and funded by NIAMS is critical to advancing the understanding of neuromuscular diseases and finding new treatments. Rare neuromuscular diseases have few treatment options and are often quite severe, so the research supported by NIAMS could truly save lives.” – Paul Melmeyer, Muscular Dystrophy Association
- “A well-funded NIAMS research portfolio is critical to sustaining progress in understanding alopecia areata. While the approval of treatments for severe disease marks a historic milestone, there remain significant unmet needs, particularly for pediatric patients and those with mild to moderate disease. Continued research to further understand underlying disease mechanisms and identify new therapeutic targets for treatment development are greatly needed and can only be achieved with robust research funded by NIAMS.” – Nicole Friedland, CEO, National Alopecia Areata Foundation
- “The International Pemphigus & Pemphigoid Foundation has led the way in voicing the needs of the pemphigus and pemphigoid community. We work closely with our partners like NIAMS to inspire policies supportive of the needs of pemphigus and pemphigoid community and other rare disease patients and their families.” – Marc Yale, IPPF
- “The National Psoriasis Foundation is pleased to be a supporting partner in the Accelerated Medicines Autoimmune and Immune Mediated Diseases (AMP® AIM) program run through NIAMS and the Foundation for the National Institutes of Health. AMP AIM and other research funded by NIAMS is critical to defining mechanisms of psoriatic disease and identifying new targets for treatment and diagnosis that will benefit our community.” Bob Friesel, PhD, National Psoriasis Foundation

Our FY 2026 funding request would enable NIAMS to continue critical research initiatives and explore new opportunities to identify causes, treatments and ways to prevent some of the most prevalent diseases and disorders in the United States. The funding request accommodates the Biomedical Research and Development Price Index as well as a 9% increase over the fiscal year 2025 enacted level for NIAMS. The requested amount represents a fraction of what is needed to adequately fund an Institute that currently is significantly underfunded relative to the disease burden within its purview.

Thank you for your consideration of our request. For additional information, please contact the NIAMS Coalition Co-Chairs, Pat Wildman (wildman@lupus.org) and Lee Grossman (grossman@oref.org)

Sincerely,

American Behcet's Disease Association
American College of Rheumatology
American Medical Society for Sports Medicine
American Society for Bone and Mineral Research
American Society of Gene and Cell Therapy
Arthritis Foundation
Arthritis National Research Foundation
Autoimmune Association
Autoinflammatory Alliance
Coalition of Skin Diseases
Dermatology Foundation
Dermatology Nurses' Association
Foundation for Sarcoidosis Research
FSHD Society
Gorlin Syndrome Alliance
International Pemphigus & Pemphigoid Foundation
International Pemphigus and Pemphigoid Foundation
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America
Lupus Research Alliance
Muscular Dystrophy Association
National Alopecia Areata Foundation
National Eczema Association
National Scleroderma Foundation
National Spine Health Foundation
Nevus Outreach
Orthopaedic Research and Education Foundation
Orthopaedic Research Society
Rheumatology Research Foundation
Sjogren's Foundation
Society for Pediatric Dermatology
Spondylitis Association of America
The Sturge-Weber Foundation
TSC Alliance
Vasculitis Foundation
VITFriends Vitiligo Support Group Inc.

The Defense Health Research Consortium

May 19, 2025

The Honorable Ken Calvert
Chair
Subcommittee on Defense
Committee on Appropriations
H-405 Capitol Building
Washington, DC 20515

The Honorable Betty McCollum
Ranking Member
Subcommittee on Defense
Committee on Appropriations
1016 Longworth House Office Bldg
Washington, DC 20515

Dear Chair Calvert and Ranking Member McCollum:

As you begin work on the fiscal year (FY) 2026 Defense Appropriations Act, we write to thank you and encourage you to continue your support for the critical and highly successful Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense (DoD). While the CDMRP funds research to protect the men and women who serve in our Armed Forces, military families, veterans, and civilian populations from a wide range of medical conditions and health challenges, many of these programs are also directly related to preparedness and response to global pandemics. We therefore encourage you to increase funding from FY 2024 levels for these critical programs by at least five percent plus inflation (approximately \$123 million increase), to ensure that our country is prepared to meet current and future public health-related threats and challenges to our national security. An increase in funding is particularly vital to mitigate the impact of inflation on the purchasing power of individual CDMRP programs, particularly those programs that have been flat funded for several years.

We also encourage you to work expeditiously to restore through supplemental appropriations the \$859 million in FY 2025 funding that was cut from the Congressionally Directed Medical Research Program (CDMRP) through the enactment of the Full-Year Continuing Appropriations and Extensions Act (Public Law 119-4). While this legislation reduced CDMRP overall by 57 percent, this reduction was not applied equally across all 35 programs. Instead, many programs vital to warfighter health -- such as traumatic brain injury/psychological health; vision and hearing, orthotics, prosthetics and spinal cord; and pancreatic, kidney and lung cancer -- received no funding for research grants in FY 2025. If not fully restored, these programs will experience research interruptions that could have long-term implications for the health and readiness of our warfighters.

The highly innovative research portfolio supported by the CDMRP fuels scientific discovery by funding high impact research not sponsored by the National Institutes of Health (NIH), the Department of Veterans Affairs (VA) or other federal agencies. Many of the programs' award mechanisms propel the exploration of revolutionary ideas and concepts. Programs focus on the potential of having a significant impact upon both their respective fields of research and the health and well-being of the men and women in the U.S. Armed Services. CDMRP awards grants to study many of the conditions -- including cancers, respiratory diseases, and other toxic exposure outcomes -- added as the result of the PACT Act as VA benefit presumptive service-connected health

conditions. Defense health research programs are worthy of continued federal support for the following reasons:

- Directly relevant to DoD-prevalent conditions: As the enclosed white paper demonstrates, the medical research programs at DoD directly impact and are aimed at improving the health and lives of current and former members of the U.S. military, their families, and the public. Programs provide groundbreaking research on traumatic brain injury and psychological health, toxic exposures including Gulf War Illness and burn pits, respiratory health, spinal cord injury, hearing and vision loss, and newer conditions such as Long COVID. Research also focuses on existing and emerging infectious diseases that may threaten operational readiness and health security, and why diseases like ALS, multiple sclerosis and Parkinson's disease occur at greater rates in those who have served in the military. CDMRP has also funded orthopedic research that has resulted in new limb-sparing techniques to save and restore functions of injured extremities, as well as outcomes research benefiting injured warfighters in need of orthotic and prosthetic devices.

Equally important, this disease-specific approach includes important medical research programs related to several forms of cancer (breast, blood, colorectal, bladder, brain tumors, lung, ovarian, prostate, stomach, liver, esophageal, melanoma, rare and childhood cancers), autoimmune diseases and other disorders (like neurofibromatosis and tuberous sclerosis complex) that have led to breakthroughs on nerve regeneration, traumatic brain injury (TBI) and post-traumatic stress disorder (PTSD).

- Complementary – and not duplicative – of other federal research: Defense health research program grants neither duplicate nor supplant NIH or VA research efforts, but rather enhance those efforts. They fund highly innovative projects – support that is typically unavailable through other federal programs. For example, programmatically-related VA research funding is only available to VA employees (at least 0.625 full-time equivalent). CDMRP funds the best-qualified proposals from researchers and research teams at top research universities and medical centers. The NIH and DoD medical research portfolios have symbiotic relationships, allowing NIH-funded basic research to serve as a foundation for ground-breaking, disorder-targeted research at DoD. NIH and DoD program officers meet regularly to ensure collaboration and prevent duplication.
- Cutting-edge and focused on cures: While the NIH funds high-quality basic biomedical research, the defense health research programs provide essential emphasis on and support for finding innovative cures or new therapies for medical conditions. For several disorders, DoD breakthroughs have led to new clinical trials, new drug products, and novel procedures that are making a difference in the everyday lives of affected patients and families. For example, research funded by DoD led to the development of two treatments for tuberous sclerosis complex approved by Food and Drug Administration.

The ALS Research Program is supporting translational research and has developed four potential treatments for the disease, for which an effective treatment currently does not exist. The CDRMP's impact is undeniable: 56 Food and Drug Administration (FDA)-approved treatments including 11 cancer drugs, a rapid blood test to detect traumatic brain injuries and more than 600 clinical trials for cutting-edge drugs and vaccines.

- Agile, adaptable, and collaborative: Each of the separate programs is guided by a specific vision and mission statement, which in addition to incorporating Congressional direction, reflect rapid change in knowledge, address research gaps, and prevent duplication. Annual funding prevents out-year budget commitments, which in turn further enhances programmatic flexibility. Many DoD programs identify, develop and fund collaborative and consortium-based research, helping to bring unique, interdisciplinary, inter-institutional, collaborative efforts to bear on complex medical research issues unlikely to be solved though the inherent limits of individual researchers.
- Competitive and unique peer review process: While Congress allocates funding through the annual Defense Appropriations Act to specific medical conditions, it does not direct the programs' dollars to specific researchers. These programs utilize an efficient multi-tiered process that includes multiple stages of peer review, including two levels of formal peer review of final proposals. Proposals are scored in a number of key areas such as scientific merit and impact for patients and the military, providing a robust comparative basis for helping accomplish the program's mission of finding and funding the best research related to these important medical conditions.
- Consumer review: All defense health research programs incorporate the full and equal participation of consumer reviewers at every stage of the multi-tiered review process – a novel and valuable practice in medical research funding. Consumers – people actually affected by the disease or medical condition – help ensure the program's funded research will have the greatest impact on those who are affected. Consumer reviewers also help inform and educate their disease advocacy communities and others.
- Generating economic growth across the United States: Research activities promote job growth and encourage long-term economic development through innovation. It has been estimated that for every dollar awarded in biomedical research grants, more than two dollars of additional business activity is created. Defense health research grants are awarded to researchers in every state in the country.

In short, the well-executed and efficient programs within the defense health research programs demonstrate responsible government stewardship of taxpayer dollars and benefit current and former military service members, the general patient population, and our nation's economy.

Perhaps most importantly, DoD's innovative approaches to funding biomedical research have led to several significant breakthroughs and achievements, contributing to national security and the.

Letter to Chair Calvert and Ranking Member McCollum
May 19, 2025
Page 4

health and welfare of U.S. Armed Forces personnel and their dependents. Continued federal funding will only build on these successes.

Lastly, we encourage timely enactment of the FY 2026 Defense Appropriations Act, to ensure continuity in the defense health research programs. We recognize the continuing challenges you must face to move appropriations bills through the “regular order” process. However, we must continue to maintain continuity in investment in this important research to ensure that our nation is prepared for future pandemics and other public health challenges that threaten our current military populations and their families, as well as veterans and the general civilian population. The failure to enact an FY 2025 Defense Appropriations Act led to the devastating 57 percent cut to CDMRP, demonstrating the importance of Congress enacting the Defense bill with full funding for CDMRP.

We, the undersigned respectfully request your support for increasing the appropriation for defense health research programs by at least five percent plus inflation in the FY 2026 Defense Appropriations Act, and restoring the \$859 million cut from the program in FY 2025.

Sincerely,

Adult Congenital Heart Association
ALS Association
American Academy of Ophthalmology
American Academy of Physical Medicine and Rehabilitation
American Association for Cancer Research (AACR)
American Association for Dental, Oral, and Craniofacial Research
American Association of Orthopedic Surgeons
American Brain Tumor Association
American Cancer Society Cancer Action Network
American College of Obstetricians and Gynecologists
American College of Rheumatology
American Gastroenterological Association
American Lung Association
American Psychological Association Services Inc.
American Society for Gastrointestinal Endoscopy
American Society of Hematology
American Urological Association (AUA)
Angelman Syndrome Foundation
Aplastic Anemia and MDS International Foundation
Arthritis Foundation
Asbestos Disease Awareness Organization
Association for Clinical Oncology (ASCO)
Asthma and Allergy Foundation of America
Autism Speaks

Bladder Cancer Advocacy Network
Blinded Veterans Association (BVA)
Cancer Support Community
Cartwright & Associates
Case Western Reserve University
Celiac Disease Foundation
Child Neurology Foundation
Children's Cardiomyopathy Foundation
Children's Tumor Foundation
Cholangiocarcinoma Foundation
Christopher & Dana Reeve Foundation
Coalition for National Trauma Research
Coalition to Cure CHD2
Colorectal Cancer Alliance
Crohn's & Colitis Foundation
CURE Epilepsy
Cure HHT
Cure SMA
CureSHANK
Danny Did Epilepsy Foundation
Deadliest Cancers Coalition
Debbie's Dream Foundation: Curing Stomach Cancer
Defense Health Research Consortium
Duke University
Epilepsies Action Network
Epilepsy Alliance America
Epilepsy Foundation of America
Epilepsy Services of New Jersey
Esophageal Cancer Action Network (ECAN)
FD/MAS Alliance
Fight Colorectal Cancer
FORCE: Facing Our Risk of Cancer Empowered
Foundation for Angelman Syndrome Therapeutics
Foundation to Eradicate Duchenne
Global Healthy Living Foundation
Global Liver Institute
GO2 for Lung Cancer
GRIN2B Foundation
Hearing Loss Association of America
Hepatitis B Foundation
HIV Medicine Association
Hope for HIE
Hope for Hypothalamic Hamartomas
Hydrocephalus Association
Indiana University
Institute for Neuro Immune Medicine
International Myeloma Foundation

Interstitial Cystitis Association
Interstitial Cystitis Association
Johns Hopkins University & Medicine
KidneyCAN
KPCOM
LGBT Cancer Project
LUNGeivity Foundation
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America
Lupus Research Alliance
Lymphoma Research Foundation
Malecare Cancer Support
Melanoma Research Foundation
Mesothelioma Applied Research Foundation
MiB Agents Osteosarcoma
Monica Weldon Consulting LLC
National Alliance for Eye and Vision Research
National Alliance of State Prostate Cancer Coalitions
National Ataxia Foundation
National Brain Tumor Society
National CMV Foundation
National Fragile X Foundation
National Health Council
National Multiple Sclerosis Society
National Psoriasis Foundation
Neurofibromatosis Midwest
NF Network
NF Northeast
Nova Southeastern University
Ovarian Cancer Research Alliance
Pancreatic Cancer Action Network (PanCAN)
Panza Maurer
Partners Against Mortality in Epilepsy (PAME)
Pediatric Epilepsy Research Consortium
Pediatric Epilepsy Surgery Alliance
Penn State University
Phelan-McDermid Syndrome Foundation
PKD Foundation
Project CASK
Pulmonary Fibrosis Foundation
Rally Foundation for Childhood Cancer Research
Rare Epilepsy Network Coordinating Committee
Research!America
Ron and Kathy Assaf College of Nursing
Sgt. Sullivan Circle
SHEPHERD Foundation
Sjogren's Foundation

Society for Women's Health Research
Society of Gynecologic Oncology
Solve M.E.
South Carolina Advocates For Epilepsy
St. Baldrick's Foundation
St. Jude Children's Research Hospital
Stony Brook University
Susan G. Komen
SynGap Research Fund, dba CURE SYNGAP1
TargetCancer Foundation
TB Alliance
The Buoniconti Fund to Cure Paralysis
The Foundation for Peripheral Neuropathy
The Kidney Cancer Association
The LAM Foundation
The Miami Project to Cure Paralysis
The National Pancreas Foundation
The Prostate Cancer Clinical Trials Consortium
The Quinism Foundation
The Society of Thoracic Surgeons
Theresa's Research Foundation
TSC Alliance
United Ostomy Associations of America
United Spinal Association
University at Albany
University of Cincinnati
University of Colorado Anschutz Medical Campus
University of Iowa
University of Pittsburgh
University of Virginia
Veterans for Common Sense
VHL Alliance
Virginia Commonwealth University
Weill Cornell Medicine
ZERO Prostate Cancer

cc: Members, U.S. House of Representatives

Enclosure: "Relevance to National Security and Military Families"

August 8, 2025

The Honorable Susan Collins
Chair, Committee on Appropriations
United State Senate
413 Dirksen Senate Office Building
Washington, D.C. 20510

The Honorable Patty Murray
Vice Chair, Committee on Appropriations
United States Senate
154 Russell Senate Office Building
Washington, D.C. 20510

The Honorable Shelly Moore Capito
Chair
Labor-HHS-Education Subcommittee
United States Senate
170 Russell Senate Office Building
Washington, D.C. 20510

The Honorable Tammy Baldwin
Ranking Member,
Labor-HHS-Education Subcommittee
United States Senate
141 Hart Senate Office Building
Washington, D.C. 20510

Dear Chair Collins, Vice Chair Murray, Chair Moore Capito, and Ranking Member Baldwin:

On behalf of the undersigned organizations, we thank you for preserving the Centers for Disease Control and Prevention (CDC) Division of Chronic Disease and within that the Arthritis Program, funded at \$9 million in the FY26 Labor-HHS appropriations bill. Our groups have collectively researched, designed, disseminated, and referred patients to evidence-based self-management programs, which are proven to help people manage their arthritis and that serve as the foundation of the CDC Arthritis Program. In April we wrote to Senate leadership expressing deep concerns regarding the Reduction in Force (RIF) that effectively shuttered the Arthritis Program. As the Senate works with the House to advance a final bill, we hope to see the Arthritis Program fully preserved and funded at a minimum of its current funding level of \$11 million.

The program currently funds 12 states and a national alliance to help implement self-management education and physical activity interventions, which are crucial for overall disease management. Importantly, through its national partnerships it has helped refer people in all 50 states to evidence-based programs. It also funds data collection of critical information about the disease, including prevalence, cost of care, comorbidities, activity limitations, and uptake of physical activity and self-management programs. Further, the program leads the work in detailing the prevalence of arthritis for critical publications for researchers and health policy analysts. Thanks to those data we know that 1 in 4 adults has doctor-diagnosed arthritis; that an estimated 78 million Americans will live with the disease in the next two decades; and that the overall economic burden associated with arthritis is over \$300 billion annually.

In addition to funding these important state efforts, the program provides assistance to national organizations that are advancing one or more of the following outcomes:

- Improved arthritis management behaviors among people with arthritis;

- Improved social and physical environments for people with arthritis; and
- Increased number of health care providers who:
 - Screen arthritis patients for function, pain, and physical activity;
 - Counsel them on physical activity; and
 - Refer to proven interventions or physical activity opportunities.

Many of the undersigned organizations receive funding that furthers one of the above outcomes. These strategies include:

- Increasing access to, availability of, and sustainability of Arthritis-appropriate, Evidence-based Interventions (AAEBIs) nationwide,
- Promoting arthritis information for the public and AAEBI referrals through a national Arthritis Helpline,
- Building partnerships and coordinating national activities to address osteoarthritis, the most common form of arthritis, and
- Providing training and technical assistance to enhance the capacity of states to effectively address arthritis.

Again, we thank you for preserving these critical chronic disease functions within the CDC and look forward to working with you to advance these policies in the coming weeks and months. Please contact Anna Hyde at ahyde@arthritis.org if we can be of assistance or provide further information or resources.

Sincerely,

American College of Rheumatology
 Arthritis Foundation
 National Recreation and Park Association
 Cheryl Der Ananian, PhD, Chair, Osteoarthritis Action Alliance
 Sjögren's Foundation
 YMCA of the USA