

May 17, 2010

Dr. Francis Collins
Director
National Institutes of Health
Building 1
9000 Rockville Pike
Bethesda, Maryland 20892

Dear Dr. Collins:

We the undersigned organizations – representatives of diverse patient communities and in many cases funders of medical research – share the common goal of translating the promising discoveries coming from basic science into new treatments and cures for the patients we serve. For that reason, the following 87 organizations support new approaches that maximize the resources of our nation's medical research enterprise and support collaboration among all the stakeholders involved. The National Institutes of Health (NIH) is, of course, at the center of that enterprise, and a key component of NIH's investment is the research effort on its own campus, the Intramural Research Program (IRP).

We have been pleased to see the NIH's Scientific Management Review Board (SMRB) take up the issue of the organization and management of the IRP, and specifically the fiscal sustainability and utilization of the Clinical Center. We are writing to offer our support for one of the actions we understand is under consideration by the Board and the NIH, and that is opening up the Clinical Center facilities for greater use by the external research community.

As you are well aware, the Clinical Center is the largest dedicated research hospital in the country, and its existence in the IRP represents one of NIH's most unique resources. It provides some of the nation's best imaging equipment, phenotyping expertise, and access to a wide range of clinical research specialists. As a world-class facility, it has the potential to excel in research efforts focused on rare and orphan diseases and on pre-clinical and methods research essential to building tools, platforms, and protocols for the entire clinical research enterprise.

Yet the Clinical Center is an underutilized facility, and its potential as a national resource for the public health is not being fully realized. We believe that allowing and promoting greater use of the facility by external researchers is an important way for the Clinical Center to not only increase its utilization but to achieve its vision to "lead the global effort in training today's investigators and discovering tomorrow's cures."

We would like to see the NIH:

- Create streamlined mechanisms by which external researchers can more fully use the Clinical Center for projects in collaboration with the IRP. This might include giving the Clinical Center and/or Institutes the flexibility and authority to negotiate broader collaborative agreements or public-private partnerships, taking into consideration ethics rules and intellectual property rights;

- Explore the possibility of the Clinical Center controlling a pool of funds to make use of the facility feasible for investigators who otherwise could not afford it, for example through a program similar to the existing Bench-to-Bedside Awards.

We thank you for the opportunity to provide this input, and we look forward to working with you to ensure that the Clinical Center's resources are being put to their highest and best use.

Sincerely,

Accelerate Brain Cancer Cure
Accelerated Cure Project for Multiple Sclerosis
Aeras Global TB Vaccine
Alliance for Aging Research
Alpha-1 Foundation
Alzheimer's Foundation of America
Alzheimer's Association
American Autoimmune Related Diseases Association
American Institute for Medical and Biological Engineering
ARPKD/CHF Alliance
Autism Society
Beyond Batten Disease Foundation
Bonnie J. Addario Lung Cancer Foundation
Breast Cancer Network of Strength
Californians4Cures
Cancer Research Institute
Celiac Disease Center at Columbia University
CHDI Foundation, Inc.
Children's Neurobiological Solutions
Children's Rare Disease Network
Children's Tumor Foundation
Chordoma Foundation
Coalition for Pulmonary Fibrosis
Coalition of Heritable Disorders of Connective Tissue
Colon Cancer Alliance
COPD Foundation
Cure Alzheimer's Fund
Curing Kids' Cancer
Cutaneous Lymphoma Foundation
Cystic Fibrosis Foundation
Damon Runyon Cancer Research Foundation
Detroit Medical Reserve Corps
Dr. Susan Love Research Foundation
Epilepsy Therapy Project
FasterCures/The Center for Accelerating Medical Solutions
FOD Family Support Group
Foundation for Prader-Willi Research
Foundation for Sarcoidosis Research
Genetic Alliance

International AIDS Vaccine Initiative
Jacob's Cure
Jeffrey Modell Foundation
Joubert Syndrome and Related Disorders Foundation
Kidney Cancer Association
Klinefelter Syndrome and Associates
Life Raft Group
LIVESTRONG
Lung Cancer Alliance
Lung Cancer Circle of Hope
Medicines for Malaria Venture
Melanoma Research Alliance
Mesothelioma Applied Research Foundation
MHE Research Foundation
Michael J. Fox Foundation for Parkinson's Research
Multiple Myeloma Research Foundation
National Eczema Association
National Foundation for Ectodermal Dysplasias
National Health Council
National Indian Health Board
New York Stem Cell Foundation
Pachyonychia Congenita Project
Parkinson's Action Network
Partnership for Compassionate Use Therapies
Prader-Willi Syndrome Association (USA)
Progeria Research Foundation
Prostate Cancer Foundation
Pulmonary Fibrosis Foundation
PXE International
Rare Disease Foundation
Reflex Sympathetic Dystrophy Syndrome Association
Rett Syndrome Research Trust
Royal National Institute for Deaf People
Sarcoma Foundation of America
Seattle Biomedical Research Institute
Society for Women's Health Research
Solving Kids' Cancer
The AIDS Institute
The Alzheimer's Drug Discovery Foundation
The Leukemia & Lymphoma Society
The Nicholas Conor Institute for Pediatric Cancer Research
The RARE Project
The Sturge-Weber Foundation
Translational Genomics Research Institute
Tuberous Sclerosis Alliance
Van Andel Research Institute
VascularCures - The Foundation for Accelerated Vascular Research
VHL Family Alliance