January 27, 2020

President Donald J. Trump
The White House
1600 Pennsylvania Ave, NW
Washington, DC 20500

Dear President Trump,

As 74 national patient and disease advocacy organizations, we are writing to express our support for a strong national Open Access policy that would guarantee immediate, free access to and full reuse of the results of scientific research that our tax dollars support. While the current U.S. policy requiring public access to taxpayer-funded research enacted in 2013 was a step in the right direction, it is simply not enough. It includes a provision that allows critical research articles to remain locked behind pay walls for a full year – a year in which patients, doctors, researchers and their families face critical decisions that could and should be informed by the latest research.

There is a profound urgency to speed up the translation of basic science into meaningful clinical interventions – treatments, therapies and cures. The research outputs resulting from U.S. taxpayer-funded research are the raw materials required to make sense of disease and mitigate its effects, and should be made immediately available. This includes journal articles funded by all federal agencies, along with the underlying data needed to validate an article's conclusions, and any corresponding software or code.

Information critical to health should no longer be held hostage by arcane publishing practices. It is time for publishers, both private and academic, to redesign their business models in response to a new age of information sharing and a stronger sense of the scientific commons. We have seen business paradigms for all kinds of publishing industries evolve as information aggregation changes. It is time for this industry to evolve as well. Public access to scientific literature is critical. It is the bedrock of our current system of discovery and the catalyst for science to build on science. Scholars and educators will find riches in new data and studies to use in classrooms; researchers across disciplines will have new opportunities for collaboration as they engage this treasure of publicly funded knowledge; and the work of all authors will be used and cited more frequently, enhancing their contributions to their field. Public access to the biomedical literature will yield untold benefits for medical research and discovery of treatments and therapies.

Today, we are among the millions facing an uphill battle, including a future of disease and disability for our children. Thousands of diseases affect millions of Americans. I have watched too many people in our community die in these years, and the time for waiting is over. So, let us not spend any more of our precious time debating and commenting on this. We live on the promise and inestimable value of publicly funded science. Obstacles to translating basic science into practice abound, but gated access is an artificial one. Remove barriers to information immediately; grant us public access to taxpayer-funded research without delay. We have a great deal of work to do, and we need the tools to do it, now.

As advocates, clinicians, patients, parents and taxpayers, we are committed to working with you, federal agencies, and researchers to ensure that the public's investment in scientific research is maximized to achieve its aim of improving the lives and welfare of all people. We urge you and your Administration to issue a policy that eliminates the current 12-month delay on articles access, and to ensure that articles and supporting data resulting from taxpayer funded research be made immediately available under terms and conditions that allow their full reuse.

Respectfully,

5p- Society
AliveAndKickn
Alstrom Syndrome International
Angioma Alliance
APBD Research Foundation
APS Foundation of America, Inc.
ARPKD/CHF Alliance
Asthma and Allergy Foundation of America
Batten Disease Support and Research Association
Bridge the Gap – SYNGAP Education and Research Foundation
Christopher & Dana Reeve Foundation
CLOVES Syndrome Community
Congenital Adrenal Hyperplasia Research Education and Support Foundation
Concert Genetics
Costello Syndrome Family Network
CureSHANK
Cure CMD
Cure HHT
Cutaneous Lymphoma Foundation
CURED Nfp
Cure Sanfilippo Foundation
Dandy-Walker Alliance, Inc
Dup15q Alliance
Family Voices
FOD Family Support Group
Foundation for Prader-Willi Research
FND Hope
Genetic Alliance
Glut1 Deficiency Foundation
Hereditary Disease Circle
HDYO Huntington's Disease Youth Organization
Inflammatory Breast Cancer Research Foundation
International Foundation for CDKL5 Research

International Pemphigus & Pemphigoid Foundation
John Thompson, PhD
K-T Support Group
LunaPBC
Lupus and Allied Diseases Association, Inc.
Lymphangiomatosis & Gorham's Disease Alliance
M-CM Network
MLD Foundation
National Blood Clot Alliance
National Neutropenia Network
National Urea Cycle Disorders Foundation
NBIA Disorders Association
NGLY1.org
Noah's Hope - Hope4Bridget Foundation
No Stomach For Cancer
RARE-X
Ring14 USA
Organic Acidemia Association
Pathways for Rare and Orphan Studies
Phelan-McDermid Syndrome Foundation
Prader-Willi Syndrome Association (USA)
PTEN World
PXE International
Queens Sickle Cell Advocacy Network Inc. (QSCAN)
SADS Foundation
Siegel Rare Neuroimmune Association
Spastic Paraplegia Foundation
SPAN Parent Advocacy Network
Stickler Involved People
Team Sanfilippo Foundation
The Life Raft Group
The Mastocytosis Society, Inc.
The RUNX1 Research Program
Sparrow Health System
Turner Syndrome Society of the United States
Usher 1F Collaborative
Usher Syndrome Coalition
Veterinary Information Network
Wilson Disease Association
Wishes for Elliott
XXYY Project

cc: Mick Mulvaney, Acting White House Chief of Staff and Director, Office of Management and Budget
Dr. Kelvin Droegemeier, Director, Office of Science and Technology Policy