

**If you want to sign your organization on to this letter,  
email [vwhittier@geneticalliance.org](mailto:vwhittier@geneticalliance.org)**

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