

## **Letter to Senate on National Institutes of Health public access policy**

October 17, 2007

To the United States Senate:

As an organization that includes more than 600 advocacy, research, and healthcare organizations that represent the interests of millions of individuals living with genetic conditions, we are writing to ask for your support to ensure that U.S. taxpayers have timely and free access to articles reporting on government-funded research. Specifically, we are interested in the inclusion of language put forth in the Labor, Health and Human Services, Education and Related Agencies Appropriations bill directing the National Institutes of Health (NIH) to implement a mandatory deposit policy for all research articles stemming from NIH-funded research. There has been extensive consideration of this change in policy and we request that the language neither change nor be removed from Appropriations measures.

American taxpayers are entitled to access on the Internet to the peer-reviewed scientific articles on research funded by the U.S. government. Widespread access to the information contained in these articles is an essential, inseparable component of our nation's investment in science.

Over the more than two years since its implementation, the NIH's current voluntary policy has failed to achieve any of the agency's stated goals, attaining a deposit rate of less than 5% by individual researchers. A mandate is required to ensure that NIH is able to track its investments and corresponding results in federally funded research, have a complete archive of this research, and enhance public access to these assets.

Thank you for considering this matter.

Sincerely,

Sharon F. Terry, MA  
President and CEO

## **Organizations**

Advocacy for Patients with Chronic Illness, Inc  
Alpha-1 Association  
Alpha-1 Foundation  
American Celiac Disease Alliance  
American Health Information Management Association  
American Syringomyelia Alliance Project  
BCCNS Life Support Network  
Biotechnology Institute  
Bosom Buddies, Inc.  
Cardio-Facio-Cutaneous International  
CARES Foundation, Inc  
Centronuclear Myopathy Project  
CFC International  
Coalition of Heritable Disorders of Connective Tissue  
COPD Foundation  
Cutaneous Lymphoma Foundation  
Cutis Laxa Internationale  
Cystinosis Research Network  
Genetic Alliance BioBank  
Genomic Health  
Hadassah, the Women's Zionist Organization of America  
Hemophilia Federation of America  
Hereditary Angioedema Association  
HHT Foundation International  
In Need of Diagnosis, Inc  
International Association of Sickle Cell Nurses and Physician Assistants  
Lymphatic Research Foundation  
Massachusetts Families Organizing for Change  
Moebius Syndrome Foundation  
National Tay-Sachs and Allied Diseases Association  
National Urea Cycle Disorders Foundation  
NBIA Disorders Association  
National Foundation for Ectodermal Dysplasia  
National Organization for Rare Disorders  
Northern Nevada Genetic Counseling  
National Niemann-Pick Disease Foundation  
Organic Acidemia Association  
Parent Project Muscular Dystrophy  
Periodic Paralysis Association  
Periodic Paralysis News Desk  
PKD Foundation  
Progeria Research Foundation, Inc.  
Project DOCC - Delivery of Chronic Care

PXE International  
SADS Foundation  
Sequenom, Inc.  
Shwachman Diamond Syndrome Foundation  
The Annie Appleseed Project  
Trisomy 9 Parent Support Group  
Us TOO - Wichita Chapter  
Y-ME National Breast Cancer Organization

## Individuals

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Lago Vista, TX  
Winchester, VA  
Atkinson, WI  
Methuen, MA  
Weymouth, MA  
Birmingham, MI  
Crossett, AR  
East Hills, NY  
Evansville, IN  
Sankara Nethralaya, Chennai, India  
Burlington, CT  
St. Paul, MN  
Ferndale, MI  
Chapel Hill, NC  
Decatur, GA  
Tucson, AZ  
Washington, DC  
Chantilly, VA  
Contra Costa County, CA  
New York, NY  
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Decatur, GA  
Reno, NV  
Boston, MA  
Baltimore, MD  
Chicago, IL  
Maiden, NC  
Atlanta, GA  
Arlington, VA  
Evanston, IL  
Columbia City, OR  
Arroyo Grande, CA  
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Celina, TX  
Iowa City, IA  
Newburyport, MA  
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