

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

Alfred Aburto	San Diego, CA
Doreen Allen	Johannesburg, South Africa
Stephen Amato	Bangor, ME
Beverly Avery	Jackson, MI
Barbara Balaban	Somers, NY
Frances Berkwits	New York, NY
Elizabeth Berry-Kravis	Chicago, IL
Selena Bluntzer	Schertz, TX
Theresa Boehm	Independence, MO
William Boorstein	Larchmont, NY
Miriam Breslauer	Farmington, MI
Susan Brust	Larchmont, NY
John Carey	Salt Lake City, UT
Mary Castro Summers	Newton, MA
Deborah Chalko	-
Catherine Chase	Fall River, MA
Robert Chase	Fall River, MA
Jeanne Clapper	Holliston, MA
Kimberly Crawford	Boston, MA
Oanh Dang	San Diego, CA
Sherry Davis	Wichita, KS
Susan Dickinson	Devault, PA
Jannine Dobson	Oconomowoc, WI
Elmer Dreyer	Glastonbury, CT
Nancy Dreyer	Glastonbury, CT
Susan Duhig	St Louis, MO
Ann Earles	Waikoloa, HI
Patricia Furlong	Middletown, OH
Micki Gartzke	Shorewood, WI
Pam Gerrol	-
Susan Hahn	Key Biscayne, FL

Donna Harbaugh	Stoystown, PA
Richard Hartin	Lago Vista, TX
Rosa Hawkins	Winchester, VA
Nadine Hill Fort	Atkinson, WI
Janet Hirschhorn	Methuen, MA
Lisa Jennings	Weymouth, MA
Judy Jones	Birmingham, MI
Vicki Keene	Crossett, AR
Jack Kelly	East Hills, NY
Jennifer L. Kennada	Evansville, IN
G. Kumaramanickavel	Sankara Nethralaya, Chennai, India
Mary Leblanc	Burlington, CT
Lisa Leslie	St. Paul, MN
Terry Mac Dermaid	Ferndale, MI
Sara Mack	Chapel Hill, NC
Penny Mahy	Decatur, GA
Kathryn L. Maish	Tucson, AZ
Monique K. Mansoura	Washington, DC
Jeanne Meck	Chantilly, VA
Laurel Moore	Contra Costa County, CA
Janice Newman	New York, NY
New York, NY	-
Tricia Page	Decatur, GA
Robbin Palmer	Reno, NV
Diana Pangonis	Boston, MA
Susan Panny	Baltimore, MD
Beverly Parker	Chicago, IL
Rodney Robbins	Maiden, NC
Peter Roberts	Atlanta, GA
Amanda Rowe	Arlington, VA
Wendy Rubinstein	Evanston, IL
Jon Saatvedt	Columbia City, OR
Molly Santa Cruz	Arroyo Grande, CA
Dawn Shabrach	Middletown, DE
Ariel Sherbany	-
John Stark	Celina, TX
Don St. John	Iowa City, IA
Mary Lou Supple	Newburyport, MA
Elizabeth Taylor DeChene	Boston, MA
Jan Thompson	Lexington, KY
Ty Thompson	Brentwood, TN
Monica Tulloss	Lexington, KY
Jeff Ungerleider	New York, NY
Hunt Valley	Baltimore, MD
Christine Vocke	Germantown, MD
Howard Winkelbauer	Munhall, PA

Lois Winkelman
Marion Yanovsky

Chicago, IL
New York, NY