



Alliance for Taxpayer Access
www.taxpayeraccess.org

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Taxpayers Support “Open Access” to NIH Research

Public Interest Advocates Join Forces to Support Congress and NIH Leadership

Washington, DC (August 24, 2004) – An unprecedented coalition of public interest groups today announced the formation of the Alliance for Taxpayer Access. The Alliance will urge the National Institutes of Health as well as Congress to ensure that peer-reviewed articles on taxpayer-funded research at NIH become fully accessible and available on line and at no extra cost to the American public.

The Alliance formation precedes the public interest meeting slated for Tuesday, August 31 where NIH will receive input on how to improve public access to the results of NIH-funded biomedical research.

The Alliance is an informal coalition of libraries, patient and health policy advocates, and other stakeholders who support reforms that will make publicly funded biomedical research accessible to the public. Details and FAQ's on the Alliance may be found at www.taxpayeraccess.org.

Today the vast majority of research funded with public dollars is available only through increasingly costly journal subscriptions (often costing thousands of dollars annually for a single journal), institutional licenses (more than a million dollars annually for many universities), or per article purchases (as much as \$30 per article). Alliance supporters believe the current system of subscription-based access to scientific research is economically unsustainable and effectively impedes the dissemination and use of research that has been paid for with public dollars.

Alliance supporter Sharon Terry, President and CEO of the Genetic Alliance, said, “This consumer-centered approach is a long-overdue means by which to enhance public health education, speed the translation of genetic advances into quality, affordable health care, and inform and empower patients in their health care decisions.”

“It is sometimes suggested that this information is not available to the ‘homemaker in Iowa’ because she is ill equipped to deal with this information. We know, from our 600 members – disease-specific advocacy organizations – that the homemaker has many resources to help her use that information. This access is critical; we know first-hand that clinicians are unable to keep up with information on 6000 rare diseases, and *patients must be the bridge to new knowledge.*”

Acknowledging the key role of individuals volunteering for clinical tests, Mitchell Warren, Executive Director of the AIDS Vaccine Advocacy Coalition, said that, "Open access is consistent with cornerstone principles of respect for persons when conducting research on human subjects and will contribute to the willingness of individuals to participate in subsequent research because they have full, shared, knowledge of results."

"In the digital age, with the extraordinary public benefits of cutting-edge research, it is counter-productive for there to be costly barriers preventing the fullest possible availability of quality information about current research findings," said Rick Johnson, spokesman for the group. Johnson also serves as director of the Scholarly Publishing and Academic Resources Coalition (SPARC), a member of the new Alliance. "We agree with leaders at NIH and on Capitol Hill that the status quo is unacceptable when most American taxpayers do not have access to the reports on biomedical research conducted with U.S. Government funds."

Barbara Redman, Dean of the College of Nursing at Wayne State University, echoed concerns of educators' within the Alliance: "Access to emerging NIH-funded medical research is invaluable to the transfer of knowledge in every instructional setting. Faculty and students alike benefit from access to biomedical reports in all fields, and we applaud NIH leadership in furthering this initiative."

Dr. Richard Roberts, 1993 Nobel Laureate in medicine and currently with New England Biolabs, added his support: "Open access to the scientific literature is the single most important advance that we can make in the distribution of research results to scientists and the public alike. I find that a majority of my fellow scientists and Nobel Laureates agree that this new initiative is groundbreaking, long overdue and will ensure that we all can read about the results of our government's support of research. I am heartened that taxpayers representing broad stakeholders in this issue have joined forces to endorse the principle of open access to the scientific literature we produce through our investment of public dollars. This is good for science and good for the American public."

Members of the Alliance for Taxpayer Access, at formation (in alphabetical order), include:

AIDS Action Baltimore
AIDS Vaccine Advocacy Coalition
American Association of Law Libraries
American Library Association
American Medical Student Association
Arthritis Foundation
Asian and Pacific Islander American Health Forum
Association of Academic Health Sciences Libraries
Association of College & Research Libraries
Association of Maternal and Child Health Programs
Association of Research Libraries
Association of Southeastern Research Libraries
Autosomal Recessive Polycystic Kidney Disease and Congenital Hepatic Fibrosis Alliance
Boston College Libraries
Christopher Reeve Paralysis Foundation
Coalition for Heritable Disorders of Connective Tissue
Colorado State University Libraries
Conquer Fragile X Syndrome
Down Syndrome Treatment and Research Foundation

Facing Our Risk of Cancer Empowered
Genetic Alliance
International Mosaic Down Syndrome Association
IsoDicentric 15 Exchange, Advocacy & Support
Medical Library Association
National Alliance for Autism Research
National Coalition for PKU & Allied Disorders
National Fragile X Foundation
National Tay-Sachs & Allied Diseases Association, Inc.
New England Biolabs
Parent Project Muscular Dystrophy
Prader-Willi Syndrome Association
Public Knowledge
PXE International
Scholarly Publishing and Academic Resources Coalition
Spina Bifida Association of America
Tourette Syndrome Association
University of Connecticut Libraries
Wayne State University College of Nursing

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