



International
Mosaic
Down
Sndrome
Association

Uniting Unique People in a Unique World

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FEDERAL RESEARCH PUBLIC ACCESS ACT OF 2006

FRANKLIN, TX, May 2, 2006 – the **International Mosaic Down Syndrome Association** (IMDSA) has announced its public support of the **Alliance for Taxpayer Access'** endorsement of the "**Federal Research Public Access Act of 2006,**" a bill introduced by Sen. John Cornyn (R-TX) and Sen. Joseph Lieberman (D-CT).

The bill requires federal agencies that fund **over \$100 million in annual external research** to make electronic manuscripts of peer-reviewed journal articles stemming from their research **publicly available via the Internet**. IMDSA is an internet-based association primarily made up of parents of children with Mosaic Down syndrome (MDS), a rare form of the genetic disorder.

Currently, the **federal government funds research** with the expectation that new ideas and discoveries resulting from the research will drive science forward, advance the economy, and enrich the lives and welfare of people in the United States and around the world. However, too often the **research funded by American taxpayers and conducted by researchers funded by public institutions is inaccessible** because it's published in journals that charge users for access. To gain **access to this research is just too expensive for most** researchers, universities, hospitals, physicians, and consumers such as the 450+ world-wide members of IMDSA.

"As a resource for **families in constant need of medical information and education** to help their loved ones with MDS, **IMDSA enthusiastically supports Senators Lieberman and Cornyn's efforts** to increase public access to research," said IMDSA President Kristy Colvin. "This legislation will make it possible for parents, doctors, caregivers, and others - in Texas and all over the country - to **access much-needed information on cutting-edge treatments and approaches** that otherwise would filter down too slowly to be useful.

"Because **MDS is extremely rare**, information on its symptoms is not easily accessible," Colvin added. "With the Federal Research Public Access Act, **everyone will benefit** greatly."

Today the Internet brings the average American access to billions of pages of information. Yet most taxpayers – including scientists – cannot gain access to all the research paid for with their taxes. The vast majority of publicly funded research is available only through increasingly costly

journal subscriptions (often costing thousands of dollars annually), institutional licenses (more than a million dollars annually for many universities), or per-article purchases (as much as \$30 per article).

The Federal Research Public Access Act of 2006 can remedy this situation, bringing free, open access to federally funded, peer-reviewed research to all Americans. The Internet makes it possible to advance these goals cost-effectively by enabling the free, online, public availability of federally funded research. This expanded dissemination will lead to increased use and application of research, which will accelerate further progress.

In addition, the bill would make it possible for research to be promptly available to every physician, educator, small business, and citizen at home, in the office, in school, or in a library.

The following agencies have extramural budgets in excess of \$100 million and would therefore be required to make their non-classified research publicly accessible: Department of Agriculture, Department of Commerce, Department of Defense, Department of Education, Department of Energy, Department of Health and Human Services, Department of Homeland Security, Department of Transportation, Environmental Protection Agency, National Aeronautics and Space Administration, and National Science Foundation. All other agencies will not be affected by this bill and journal subscriptions will still be protected because the federally funded research is just a portion of what the science journals publish.

For more information on the Federal Research Public Access Act of 2006 you can visit <http://www.taxpayeraccess.org> More information about IMDSA can be found at www.imdsa.com