



August 14, 2009

The Honorable Senator John Cornyn  
United States Senate  
517 Hart Senate Office Building  
Washington, DC 20510  
Via Fax: (202) 228-2856

Dear Senator Cornyn,

On behalf of Genetic Alliance, I want to express my gratitude for your continued leadership in revolutionizing access to information, as evidenced by your introduction of the *Federal Research Public Access Act*, S. 1373. This legislation embodies principles that promote access to high quality information by individuals and families, and facilitate novel partnerships in research.

Under the old model, when individuals and parents would seek out results of publicly funded research to better understand the forces affecting their family, including healthcare, they encountered significant financial barriers to proactive engagement—expensive journal subscriptions, institutional licenses, and per-article purchases. The *Federal Research Public Access Act* addresses these hurdles by creating permanent online repositories that allow free public access to peer-reviewed research from eleven federal agencies. The bill's inclusion of a six-month embargo period strikes a key balance between the interests of publishers and the rights of taxpayers to reap the greatest benefit from their investment and to access credible, quality, up-to-date information. Making this information available in a free, universal, and timely manner represents a key stepping stone toward achieving a consumer-focused healthcare model that emphasizes individual responsibility for health.

More expansively, the *Federal Research Public Access Act* will facilitate innovation and accelerate the conversion of discovery to public services across a range of disciplines. For too long research results have been fragmented and segmented in silos that stifle progress. This bill provides a systemic response that seizes the energy inherent in the unimpeded and interconnected flow of information to all stakeholders who can use, adapt, or benefit from its existence. The bill allows research communities to harness technological innovation through open, digital repositories and to step into the future as collaborators who build shared infrastructure and solutions that accelerate our work beyond what anyone can do alone. The bill will propel interdisciplinary partnerships and collaboration by enhancing the transparency of publicly funded research.

T: 202.966.5557  
F: 202.966.8553

4301 Connecticut Ave., NW  
Suite 404  
Washington, DC 20008-2369

info@geneticalliance.org  
www.geneticalliance.org

Genetic Alliance applauds you in your visionary support of this legislation that holds great potential to revolutionize access to information and dissolve boundaries between stakeholders and systems. As we plow forward in this information age, we look forward to collaborating with you in identifying opportunities to enable new solutions for the proactive management of health, consumer-driven healthcare, and novel partnerships and collaborations in research. Please let us know how we can help.

Sincerely,



Sharon F. Terry  
President & CEO

*About Genetic Alliance*

*Genetic Alliance transforms health through genetics, promoting an environment of openness centered on the health of individuals, families, and communities. Genetic Alliance brings together diverse stakeholders that create novel partnerships in advocacy; integrates individual, family, and community perspectives to improve health systems; and revolutionizes access to information to enable translation of research into services and individualized decision making. For more information about Genetic Alliance, please visit:  
<http://www.geneticalliance.org>.*

Contact:      Andria Cornell, Advocacy and Health Policy Coordinator  
[acornell@geneticalliance.org](mailto:acornell@geneticalliance.org), (202) 966-5557 x207