



Archived Policy Statement

Comments to the National Institutes of Health on Open Access Policy

Presented by Sharon F. Terry, MA on March 20, 2008

I am the president and CEO of Genetic Alliance. Genetic Alliance transforms health through genetics. We accomplish this by integrating individual, family, and community perspectives to improve health systems and services; bringing together diverse stakeholders to create novel partnership; by promoting individualized decision-making through increased access to information.

Genetic Alliance's network includes more than 650 disease-specific advocacy organizations, and hundreds of partnerships with universities, companies, government agencies, and policy organizations. The network is an open space for thousands of shared resources, hundreds of creative tools, and dozens of dynamic programs.

We applaud the Congress for enacting the policy expressed in Division G, Title II, Section 218 of PL 110-161 (Consolidated Appropriations Act, 2008) and National Institutes of Health (NIH) for implementing this mandatory open access policy. We are pleased by this action, but are also acutely aware of the profound urgency inherent in a society that requires accelerated translation of basic science to meaningful clinical interventions.

All information, the raw materials of making sense of disease and mitigating its effects, should be immediately available. We ask that the NIH go a step farther and make submission of articles mandatory at six months, as a compromise to immediate access.

We live in an age of an overabundance of information. Information is not a scarce commodity anymore. Material that is 12 months old is OLD. It is unconscionable that scientific information is not immediately available to everyone. While publishers argue that they create value around the raw information, we would argue that scientists, funded with federal tax dollars and so stewards of the public trust, infuse these articles with value. There is no doubt that publishers add value, and that the value proposition around this body of knowledge should be paid for—but not the research results themselves. It is the duty of NIH, as the primary funder of biomedical research, to facilitate sunshine on this data, to bring these articles into the public commons as quickly as possible.

Information critical to health and biomedical research should no longer be held hostage by arcane publishing practices. It is time for publishers, both private and academic, to redesign their business models in response to a new age of information sharing and a stronger sense of

the scientific commons. The myriad solutions, proposed and in use, simply reformulate the walls of silos. Only a central repository will allow the necessary linkages. We have seen business paradigms for all kinds of publishing industries evolve as information aggregation changes. It is time for this industry to evolve as well.

Public access to scientific literature is critical. It is the bedrock of our current system of discovery and the catalyst for science to build on science. Scholars and educators will find riches of new data and studies to use in classrooms; researchers across disciplines will have new opportunities for collaboration as they engage this treasure of publicly funded knowledge; and the work of all authors will be used and cited more frequently, enhancing their contribution to their field. Public access to the biomedical literature funded by NIH will yield untold benefits for medical research and discovery of treatments and therapies.

I also stand here today as the mother of Elizabeth and Ian Terry, two children with a genetic disease. It is rare, not well understood, and without a treatment. We are facing an uphill battle, and a future of blindness for the two of them and thousands more with this disease. Another 6,000 or so genetic diseases burden more than 25 million Americans. When I began speaking about public access, I tried to carefully counter all of the arguments with which the publishers came forward. My thinking has evolved—while I once thought we should move carefully and try to ease into these paradigm shifts, I think now, years later, we have evidence that public banking of the genome, journals that have three-month embargos and then open access, and “the commons” of information are thriving. I have also watched thousands of people in our community die in these years, and the time for waiting is over.

Let's do it; let's not spend any more of our precious time debating this, commenting on this. We live on the promise and inestimable value of publicly-funded science. Obstacles to translating basic science into practice abound, but gated access is an artificial one—remove barriers to information immediately—open access to publicly-funded research without delay. We've got a great deal of work to do, and we need the tools now.