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Committee on Oversight and Government Reform

Written Public Testimony of

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Chairman Clay, Representative McHenry, and Committee Members, thank you for the opportunity to testify at this hearing on Public Access to Federally-Funded Research.

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, by bringing together diverse stakeholders to create novel partnership, and by promoting individualized decision-making through increased access to information.

Genetic Alliance's network includes more than 1200 disease advocacy organizations, and thousands 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.

I am also a mom of two children diagnosed with pseudoxanthoma elasticum (PXE) in 1994. My husband (a trade school graduate) and I (a college chaplain) stole access to medical libraries, and

hacked into Internet Grateful Med, and ultimately read 400 articles on this disease. As a result of what we learned, we founded PXE International, created a biobank, cloned the gene, created a diagnostic test and initiated clinical trials. We are the ordinary American public and our access to these articles has been critical. Imagine if we have open access.

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. This was a step in the right direction, and we 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. This includes journal articles funded by all federal agencies.

Some say that only academicians and scientists at major institutions need access to journal articles. Not so. We live in an information age that can and will thrust us into a new age of innovation in health and healing. This requires multidisciplinary articles in the hands of patients, parents, students, engineers, entrepreneurs, and scientists. 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 the federal government to facilitate sunshine on this data, to bring these articles into the public commons as quickly as possible.

Information critical to health 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. 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 in 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 will yield untold benefits for medical research and discovery of treatments and therapies.

Today, we are among the millions facing an uphill battle, including a future of disease and disability for our children. Thousands of diseases affect millions of Americans. I have 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 – grant us public access to publicly-funded research without delay.

We've got a great deal of work to do, and we need the tools now.

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