

Sharon Terry

In the public interest

Open access

My children have a genetic disease. It is rare, not well understood, and there is no treatment or cure. However, the most disturbing obstacle we face is the wall around published scientific research. Information critical to health and biomedical research is held hostage by questionable and 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.

In 1994, my two children were diagnosed with pseudoxanthoma elasticum (PXE), a disease that disfigures their skin, may rob them of their sight, and could cause gastrointestinal and cardiovascular difficulties. While important to my family, these details are hardly significant given the greater obstacles we face. In this age of accelerated discovery and robust raw materials—the complete sequence of the human genome, for example—it will be possible to treat and cure diseases, but only if the raw materials are available to the right partners—researchers, clinicians, and patients.

A crash course in access to medical literature

Information is a powerful raw material, but the work of improving health through biomedical research is made more difficult because of current barriers to information. These barriers shocked my husband and me as we began to make sense out of our children's disease. In response to their diagnosis, we began to research their condition.

Coming into the medical research world from nonscientific occupations, we set out in search of meaningful and new information. After discovering that bookstores did not have the information we needed, we turned to medical school libraries and began to access medical journal articles. We learned that research on PXE was a cottage industry, and, if we were to improve our children's futures, we would have to catalyze research. Our first step was to understand what we were reading. We bought textbooks and dictionaries and taught ourselves this new language word by word.

We spent hours copying articles from bound journals. But fees gate the research libraries of private medical schools. These fees became too costly for us to manage, and we needed to gain access to the material without paying for entry into the library each time. We learned that by volunteering at a hospital associated with a research library, we could enter the library for free. After several months of this, policies changed and we resorted to masking our outdated volunteer badge and following a legitimate student (who would distract the guard) into the library. When that became too risky we knew we would have to find a way to access information in a more cost-effective and reasonable manner.

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Although the United States wisely invests billions of dollars in biomedical research through the National Institutes of Health (NIH), we discovered that the results are locked up in very costly annual journal subscriptions and institutional licenses that can cost thousands of dollars for a single journal, or made scarce by use-limiting, per-article charges that can run as much as \$30 to read a single study. Therefore, we had no problem with devising schemes to hack into the early databases—Internet Grateful Med and university-based text based systems—in order to get the information we believed belongs to the public.

Founding a research organization

As a result of our research, we founded a nonprofit organization to advance research on PXE—one that would initiate and fund research and provide information to newly diagnosed individuals. Our need to read medical literature grew as our foundation grew—we were the sole source of accurate information for more than 3,000 people, and we coordinated 19 laboratories. We were co-discoverers of the gene, the first lay co-inventors of a gene patent, and are now the creators of a genetic test for PXE. I also now lead the Genetic Alliance, a coalition of 600 disease-specific and community organizations seeking better healthcare and treatments.

Today, ten years after our children's diagnosis, I can use a wonderful, freely accessible tool created by the National Library of Medicine (NLM), called PubMed. I can call up bibliographic information on the hundreds of papers relative to PXE in a few seconds. Further, I can narrow the field to just a dozen papers on which I have been an author. Then, as I click on each article, I am not able to access any of them. They exist on the Internet, but they are behind firewalls built by journal publishers that require money to release their treasure. Each one requires \$25, \$30, or \$40! Therefore, I am still forced to do end-runs around the system. I travel to libraries and photocopy,

I hire students in large medical schools to go to the stacks and copy articles for me, I borrow the journal login information from colleagues.

Who really owns NIH research?

If families are effectively barred from having access to these articles, what of the effect on researchers and clinicians with limited budgets striving to make new discoveries? Or on educators sharpening the skills of the next generation of medical practitioners? We learned that these fees were a burden to libraries, and that only the largest schools could afford the full complement of journals. We also learned that other clinicians—social workers, physical and occupational therapists, genetic counselors—don't usually have access either. Our experience forces us to ask the hard question: Who really owns the NIH biomedical research we fund with our tax dollars?

We are aware that too often scientists and medical journal publishers dismiss a parent's ability to read a scientific article or even to imagine they might share one with their medical specialist. We see how the barriers to access to publicly funded science are part of a larger system that seems to place a higher value on prestigious publications, tenure, and continued public support than on ensuring the most rapid exchange of knowledge to ease human suffering. We know firsthand that many families struggling with the added cost of medical specialists are forced to spend hundreds of dollars more each year to purchase published studies that chart the legitimate scientific progress about their loved one's disease. In some cases, this is the only credible information available. How can we justify such a high price tag on this life-sustaining public knowledge? First we pay to fund the research, and then pay again to read the outcomes.

A few hundred years ago, before moveable type, cloistered monks created rare and beautifully illuminated manuscripts containing divine word, unavailable to the illiterate masses. Distribution of this infor-

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mation was almost impossible, and these monasteries became the guardians of sacred texts. Generations later, with our newfound ability to digitize and archive information on the Internet, shouldn't we abandon our self-imposed monasteries and use existing distribution mechanisms to accelerate the spread of peer-reviewed medical science? My family knows this is critical to their health and so do the millions more who participate in clinical trials, who pursue scientific inquiry, or whose lives are uncertain until a treatment breakthrough is developed.

In addition to advocating for genetic diseases, I now also advocate for access. For me, it is all part of a continuum. Access to information leads to novel discoveries, collaborations, and discoveries that offer us solutions. Genetic Alliance joined the Alliance for Taxpayer Access, a diverse and growing alliance of organizations, founded by librarians, that represents taxpayers, patients, physicians, researchers, and institutions that support open public access to taxpayer-funded research.

Unlock the science!

New notions of cooperation, collaboration, transparency, and access are now challenging the status quo. It is now time to unlock this science and make it more accessible to all of us. Fortunately, change is in the works. NIH Director Elias Zerhouni confirmed some months ago that the status quo is unacceptable. In fact, under his direction and endorsed by the U.S. House of Representatives, NIH has implemented a cost-effective and balanced policy that, for the first time,

will make virtually all NIH-funded research free and accessible online to all Americans through the NLM.

NIH recommends that authors deposit their articles in PubMed Central, a repository managed by the NLM, anytime up to 12 months after publication. NIH itself will benefit by maintaining an archive of the articles resulting from the research it funds with public dollars.

It remains to be seen whether this system, which puts the onus on scientists, will work. Zerhouni has established an NIH Public Access Working Group of the NLM. I have accepted an invitation to serve on this committee and I hope we analyze the effects of the current policy. I see this policy as a first step. Ultimately we would like all government agencies to require that published papers resulting from publicly funded research be deposited in PubMed Central, or similar repositories, with no embargo. I recommend that these articles be the final edited versions, with links to the journals on the publishers' sites. A number of publishers, particularly academic societies, have succeeded in releasing papers with no embargo; they have not lost revenue, and realize that journals will continue to make money in subscriptions, provided they engage in the value-added practices that are so successful—providing information ancillary to the published articles that enrich the reader's understanding of the field and support the community of researchers.

Further issues: PubChem

I also hope that the NIH Public Access Working Group will consider the issues surrounding PubChem. PubChem is the latest member of the powerful family of integrated databases operated by NLM. PubChem connects chemical information with biomedical research and clinical information in a connect-the-dots fashion and is a critical part of the NIH Molecular Libraries initiative. The integration of these databases makes the whole much greater than the sum of its parts. It is a free, publicly available database that

provides information about potential starting points for the development of new drugs.

The American Chemical Society (ACS) is challenging its existence, even though there is very little overlap with the ACS's databases: PubChem focuses on the biomedical applications of small molecules, while ACS's databases focus on the chemical and patent literature. Although some of these academic societies claim to be more purely motivated than the commercial publishers, it is apparent to me that they too are motivated primarily by business interests. Disclosure is critical here, and cloaking the desire for increased profits with an academic mantle is troubling. PubChem should be celebrated as an exemplar of connected information providing a premise for accelerating research, not challenged by the business arm of a scientific society. There appears to be a conflict of interest here, and I look forward to the ACS member who will sit on the working group commenting on this.

Public access to literature is critical. It is the bedrock of our system 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 scan this treasure of publicly funded knowledge; and the work of all authors will be used and cited more frequently, enhancing their reputation and contribution to their field.

For the rest of us, living on the promise and inestimable value of publicly funded science, we will have access to the information we need to educate our doctors and to help the research community make connections as the basis for translating basic research into treatment and cures. We have no time to lose: we need public access to government-funded science now. //

Keep up-to-date on scholarly communication issues

ACRL's Scholarly Communication Web page is home to a range of resources that will keep you informed about the latest issues in the scholarly communication arena and the work ACRL is doing to help reshape the system. Visit the site to find:

Information on ACRL's Scholarly Communication Initiative

ACRL's Scholarly Communication Toolkit, with valuable information for librarians, faculty, academic administrators, and other campus stakeholders

ACRL documents, such as the Scholarly Communication Research Agenda and Open Access and the ACRL Serial Publishing Program (white paper)

Links to articles from the *C&RL News* scholarly communication column

Access this and other strategic information at www.ala.org/ala/acrl/acrlissues/scholarlycomm.

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