

**Statement of
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Autism Speaks**

**Before the
Subcommittee on Information Policy, Census and National Archives
Committee on Oversight and Government Reform
Regarding Public Access to Publicly Funded Research**

July 29, 2010

Chairman Clay, Ranking Member McHenry and members of the House Oversight and Government Reform Subcommittee on Information Policy, Census and National Archives - thank you for the opportunity to testify today on the important issue of improving public access to the results of federally funded research. I am speaking on behalf of Autism Speaks, the nation's largest autism science and advocacy organization. (I ask that my full statement be included in the hearing record).

I am here today as a scientist with a Ph.D. in Neuroscience who serves as the Vice President for Research at Autism Speaks, a non-profit organization which invests \$20-30 million in annual funding for research into the causes, prevention, treatments and, ultimately, a cure for autism. The organization is also dedicated to raising awareness of the spectrum of autism disorders and, crucially, to advocating for the needs of individuals with autism and their families.

I am also speaking to you today as the architect of the first public access policy for a US-based non-profit advocacy organization, which was implemented by Autism Speaks in December 2008. For the reasons I will describe, we believe our policy is an important first step toward transparency and accountability of the outcomes of funded research in the US. We fully support expanding access to research results – especially

to that crucial subset of scientific findings that are produced as a result of our nation's collective \$60 billion annual investment in biomedical research.

Today I'd like to very briefly underscore the importance of opening access to the results of publicly funded research to a not-for-profit research organization such as Autism Speaks from 3 perspectives:

- 1) that of the families affected by a disorder such as autism;
- 2) that of an active scientist who needs access to effectively do her job; and
- 3) that of a funder that needs to achieve our mission and provide accountability to our many stakeholders while doing so.

First: Access to the results of research generated using public funds is important to families.

The main motivation for my being here today in support of open access is the desire to improve the lives of individuals with autism and their families. Autism is a challenging disorder that now impacts nearly 1:100 children in the United States. Characterized by varying degrees of impairment in communication skills, social interactions, and restricted and repetitive patterns of behavior, individuals with autism

often require life-long support. Other than behavioral interventions which result in highly variable outcomes, there are currently no effective treatments that address the core symptoms of autism, and families are left to handle the situation as best they can.

For decades, parents and care-providers have cobbled together intervention approaches as they best see fit. I spend much of my time traveling the country to lecture to these families about the science of autism, the progress of research, and the hope that it is bringing. Families with autism are, by nature, motivated advocates constantly seeking new and reliable information to educate themselves and I have found them to be particularly sophisticated in their ability to read and interpret scientific literature pertaining to autism. Giving individuals with autism and their families access to the latest research findings empowers them to be better, more informed advocates by allowing them to read, first-hand, what progress is being made on various research fronts.

However, because of what amounts to a seemingly arbitrary barrier to accessing published research literature, they have to struggle to find the most credible information necessary to make informed decisions. In today's information age, where essentially anything said by anyone can be made accessible within a matter of

moments, it is unfortunate that families have easy access to all BUT the most scientifically valid information, that which can be found in scientifically reviewed research literature. Perhaps twenty years ago, when we still relied on the slow transfer of information through printed format, restricting access to a subset of knowledge had less of an impact. In 2010, families are inundated with information that may not always be credible, and yet they are unable to read the most scientifically rigorous data. It's time for that to change.

Second: Access to the results of research generated using public funds is required for me as a scientist to do my job.

As a scientist and, particularly, as the Vice President for Research, I am tasked with providing counsel on investing ~\$30 million in research funding for Autism Speaks annually. To carry this out, I must have access to the most complete and up-to-date scientific research finding in areas as diverse as neuroscience to nutrition. Just as any academic researcher, I am responsible for actively pursuing the literature, analyzing the reports, interpreting the data, and determining where the holes are that must be addressed.

However, in 2004 when I made the decision to leave academic research to direct research in the context of an advocacy organization I had no idea that a major hurdle

would exist to keep me from effectively achieving these goals. On a Friday I finished my research associate position at the Salk Institute in La Jolla, CA, where I had full access to scientific literature. On a Monday I started my new position as Science Director of an international research sponsoring organization, and had none.

To my dismay, I was being asked to strategically direct limited resources and make allocation decisions without knowledge of the latest research! While I was accustomed to skimming dozens of articles a week, I soon found that I had to pay what could be up to \$30 a paper. Worse yet, many of these were research reports sponsored by my own organization, but I still had to pay to read them in their final format. To provide an example of the scope of the problem, reading all the papers published in autism in 2009 could amount to \$120,000. The non-profit organization I worked for could not absorb these costs, so I relied on colleagues in the academic world to share copies of published papers. This occupied a large amount of time that would otherwise have been spent in further pursuit of effective treatments for autism.

To this day Autism Speaks' grantees and fellow scientists are shocked to find out that our organization does not have free access to these articles. Thankfully I now have a faculty appointment at Stanford University Medical School and, while I do not get paid for this position, it is worth any extra responsibilities I have taken upon as it

allows me to have access to a full library catalogue, one which I use to do my real job at Autism Speaks.

I want to emphasize this is not unique to Autism Speaks. It is not financially possible for not-for-profit funders of health research and training to subscribe to the full range of scientific journals needed do their work. In fact, last month, because of the exact issues I have just laid out, science officers of funding organizations that are members of The Health Research Alliance, a consortium of non-governmental funders of health research, issued a query on their member listserv concerning how they might obtain access to the science literature. Unfortunately, although a great deal of interest was expressed in gaining online access to the science literature, members reported it currently does not appear feasible to purchase access even by banding together. Presumably, just as I have done with my faculty appointment, everyone will have to find their own work-around.

Finally, I also want to emphasize this barrier is not exclusive to science duties. My colleagues in our government relations division, some of whom are here today, cannot access the primary research literature required to substantiate their policy recommendations and legal arguments.

In sum, there is an entire segment of scientists and health advocates who are blocked from effectively doing their jobs without access to this literature.

Third: Access to the results of publicly funded research is important to pursue the mission of Autism Speaks.

The mission of Autism Speaks is to improve the future for all who struggle with autism spectrum disorders, and we are dedicated to funding global biomedical research into the causes, prevention, treatments, and cure for autism. Our goal is to translate research discoveries into diagnoses and treatments that will have a real and *tangible* impact on the lives of individuals with autism and their families. Research is an iterative process, with each finding building upon previous findings, piece by piece. Research is also self-correcting; it requires independent validation to progress. Therefore, from the standpoint of the mission of Autism Speaks, I cannot stress how important it is for research findings to be in the public domain; funding organizations such as ours can support as much research as they wish, but unless the knowledge is utilized by others, it remains useless.

Specifically, in the case of autism, given its complex biological and behavioral nature, scientific progress will require the continuous influx of new ideas from multiple and disparate disciplines. When you are a parent of a sick or impaired child, there can

never be enough minds thinking about your problem. And unfortunately, just as there are scientists such as myself who are currently denied access based on our employment situations, there are also academic researchers in less developed countries who cannot afford journal access (and who, ironically, email to ask me for copies of articles). Similarly, there are researchers in non-academic environments, and even lay people, who want to devote their minds to autism, but they cannot gain access to the literature to study it. Again, from the perspective of Autism Speaks, if your mission is to improve the lives of persons with autism, and urgency is a core value, why would we want to keep knowledge restricted? We believe it is critical that the research papers that result from public funding be readily available to anyone with an interest in autism research. Better access to this information can only lead to positive things, whether it's more effective advocacy or further research advances.

Additionally, moving precious literature into public access will advance research discovery by allowing better archiving of scientific material and permitting database integration, two capabilities which may not have been at issue when the current limited access parameters were originally established.

Finally, as a non-profit organization utilizing donations from generous benefactors, we must be held accountable in pursuit of our mission. Typically our donors are the

families of the very individuals we are aiming to help, many of whom are already financially struggling due to the heavy cost of autism care – an estimated \$3.2 million in incremental costs over the lifetime of an individual with autism. Opening access to research results plays a role here, too. When speaking of our accomplishments or making the case for continued investment, it is exceedingly important for donors to Autism Speaks, or to other non-profits, or even taxpayers to NIH, to have the ability to see the outcome of their investments and the impact of those investments on reducing disease burden. I find it extremely difficult to explain to a stakeholder that has provided me with the money to pay for the research, that they have to pay once again to see the results of that research.

As I noted earlier, Autism Speaks is perhaps uniquely qualified to call for expanded access to the results of publicly funded research, because we as a funding organization have committed to not only “talking the talk” about greater access, but also “walking the walk.”

Autism Speaks invests several million per year in original autism research. To ensure that this investment is fully leveraged – that as many people who might want to have access to the results of research can do so as soon as possible, to begin to understand it, and to build on it, in 2008 we implemented our own “public access” policy – to

require that any researcher that receives grant funding from Autism Speaks to agree to make a copy of any article resulting from that funding freely, publicly accessible through an online public site no later than 12 months after publication in a peer-reviewed journal.

We modeled our policy on the highly successful public access policy of the National Institutes of Health (NIH) and, in fact, chose the PubMed Central Data database maintained by the NIH as the repository into which all Autism Speaks funded research papers will be deposited. Since that time, I have been contacted by several other non-profit advocacy organizations interested in following our model, and it is my understanding that this Fall, CURE Epilepsy will announce a policy that is based upon ours. This is perhaps the best proof that what I have spoken of today is not about autism per se, but about the fundamental need to change the way stakeholders – parents, providers, scientists and advocates – are finally included in the discovery process.

FINAL SUMMARY

Opening up public access to the results of publicly funded research has enormous potential benefits – not just for families affected by conditions like autism, but families of all kinds with an interest – or a need – for information on a broad spectrum

of biomedical research that affect their lives. It has the potential to greatly enhance the ability of scientists like me, who, quite simply, **require** access to scientific results to be effective – as researchers, and also as scientists tasked with helping organizations of all kinds make the most informed decisions possible about investing scarce research dollars into the most promising research avenues. Opening up access to publicly funded research has the potential to help myriad other organizations like Autism Speaks accelerate their quest to achieve their missions – benefiting not only science, but countless members of the public by speeding up progress towards breakthrough discoveries, treatments and, eventually, cures.

Thank you once again for providing me with the opportunity to speak about this very important issue.