

Why is Public Access Important for Non-Profit Advocacy Organizations?

Sophia A. Colamarino, Ph.D.

Consulting Associate Professor, Psychiatry

Stanford Medical School

Director, Science & Health Programs

J & M Goldman Foundation

(FORMER Vice President of Research, Autism Speaks)

Berlin9

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Reason 1: My Job

(I'm a scientist without an institution!)

My Job

I'm being asked to strategically direct resources without information?

(\$12 a paper?? No way!)

I REFUSE to pay twice

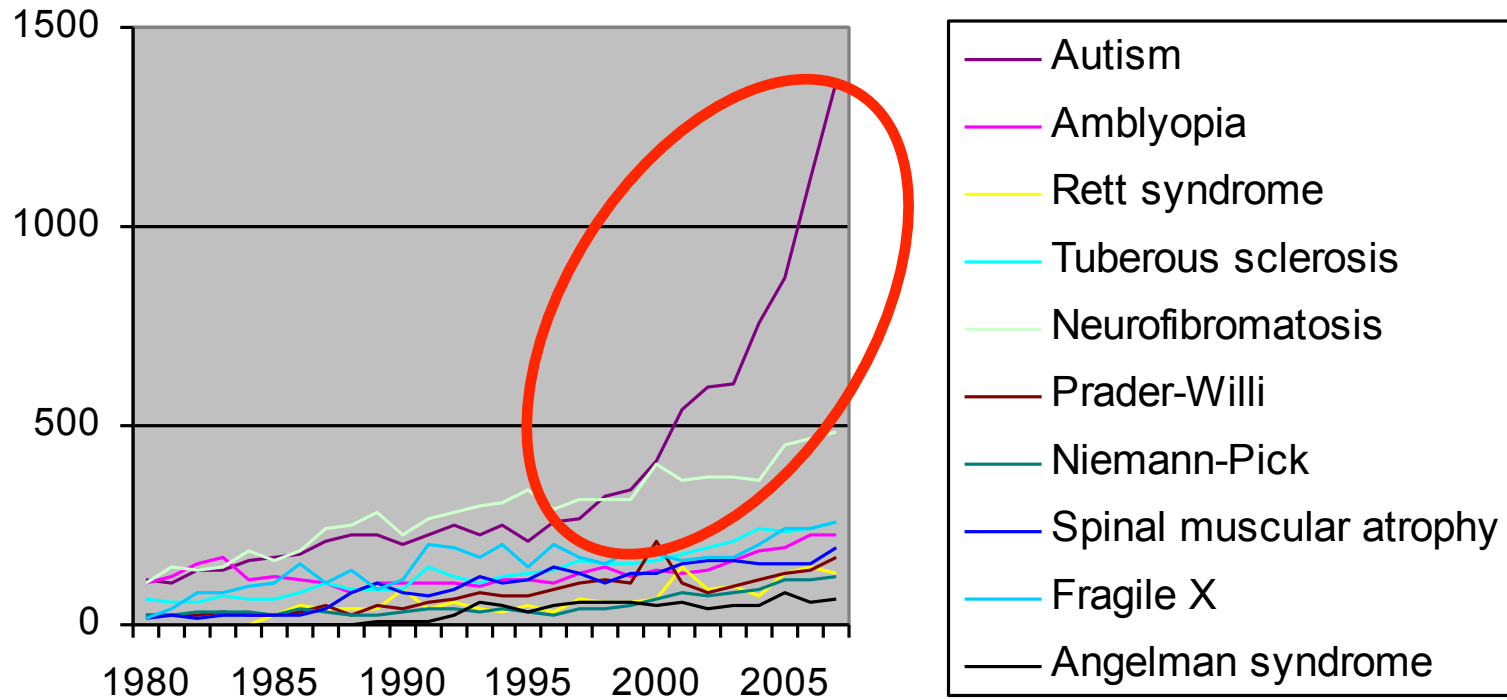
(Found a workaround and moved on...)

Reason 2: **The Families**

(How do I convince them research is making progress?)

The Amazing Rise of Autism Research

Publications in PubMed



Families: Power of an informed population

- I lectured constantly to families/careproviders about the biology of autism, the newest research and *the hope it's bringing*
 - I have found them to be 1) *motivated and educated* advocates, constantly seeking reliable information, and 2) *sophisticated* in their ability to read and interpret scientific literature
 - Providing access *empowers* them to be better, more informed advocates and gives them a *positive* outlet by allowing them to participate in progress first-hand
 - Artificial barrier to accessing published research literature causes families to struggle to find the most rigorous data necessary to make informed decisions
 - In today's information age people are inundated 24/7 with info that may not always be credible....
- ➡ Families have easy access to all BUT the most scientifically valid information!

Does this make sense?!

Reason 3 : **The Foundation**

(How do I show we are accountable?)

Open Access Furtheres Ability to Achieve Mission

- Mission: translate research discoveries into diagnoses and treatments that have tangible impact

OA increases spread/impact of knowledge (previous speakers)

- Inherent “PR Value”: for a relative of sick or impaired loved one, there can *never* be enough minds thinking about your problem

OA gives everyone access (researchers in third world; lay people etc)

- Major Donors: When making the case for continued investment, exceedingly important for donors to see

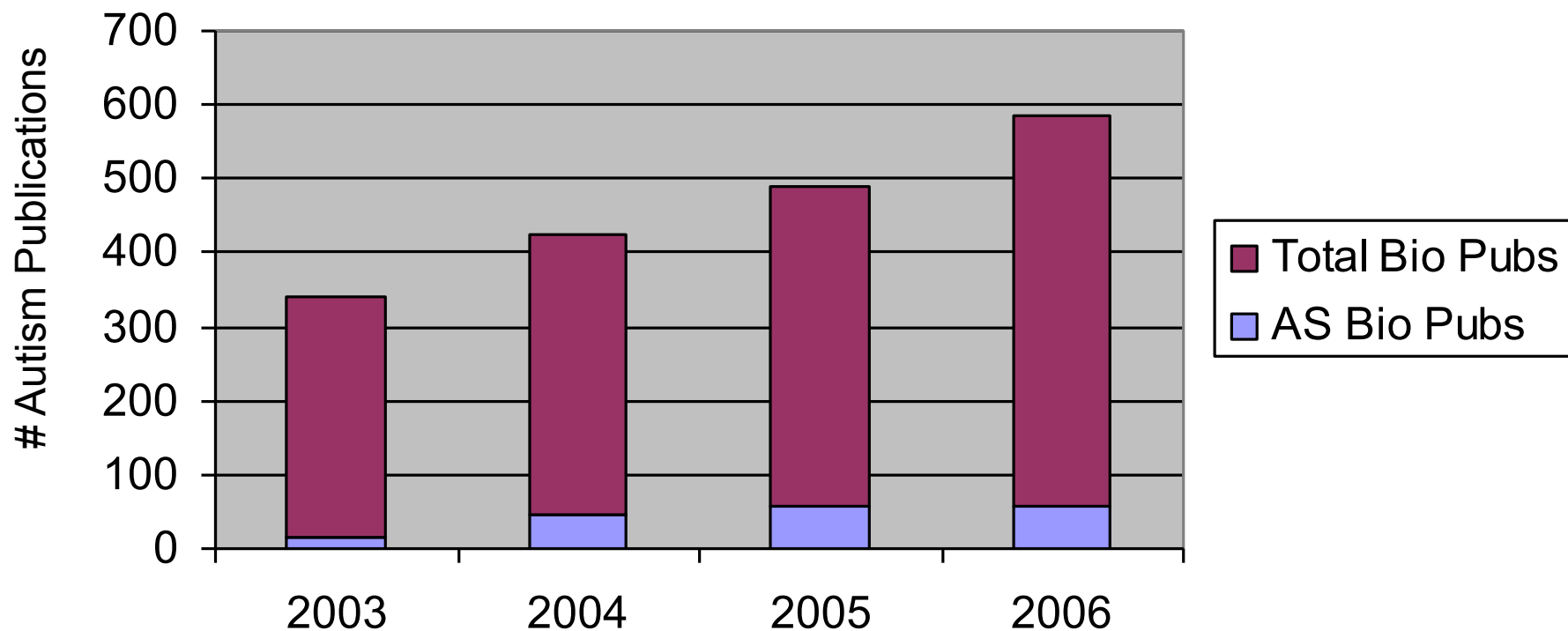
1)outcome of their investments

OA allows donors to see physical embodiment (& acknowledgement) of their investment

2)impact of those investments on research progress

OA allows better tracking of accomplishments and development of metrics

Autism Speaks' (AS) Contribution to Autism Research



Entrez Pubmed!

Pubmed tracks funders on back end – why?

Enter David Lipman (NCBI), Rick Johnson (ARL),
Ed Sequiera (NLM)

Offered up Autism Speaks as test case for PubMed Central

A year to hammer out policy and deposit mechanism

The Policy

Deposit manuscripts in PMC after 12 mo hold-back

Prospective only

Grantees accept burden to:

- Inform themselves about policy of journal publisher

- Secure necessary copyright to comply

- Deposit electronic manuscript thru deposition portal
and associate it w/AS grant #

AS does not pay for fee-based open-access (mixed model)

TOP

10

Autism Research Events of 2008

Groundbreaking Policy Brings Research Findings to the Public

*Autism Speaks becomes the first US disease advocacy group
to require their funded research be made freely available*



PubMed
Central



AUTISM SPEAKS™
It's time to listen.

This represented for us...

**A fundamental change in the way
stakeholders**

– *parents, providers, and advocates* –

are finally included in the discovery process

Some worrisome equivalencies I' ve been hearing ...

- Publication' s impact = maximizing opportunity to problem solve/effect change
- Public Access ≠ inability to publish in journals with high impact factor
- Public Access Policy = paper must be deposited in publically-accessible database
- Public Access Policy = welcomed by grantees

Some thoughts as you move forward...

Craft a policy

Don't reinvent the wheel

Provide templates

Inform publishers

Consider compliance your friend

Work with PMC & SPARC/ARL as partners

The hope is that...
*“these efforts will create a snowball effect
that sets the standard for other funders
to make access to their research publications
freely available.”*

Me, 2008

But A Whiff of Change Is In Air:

- Rockefeller/PLoS Meeting: Convened funders. They requested matrix of different OA policies & materials to convince Boards of utility.
- HRA: Created subcommittee. Put together Public Access Tool Kit rolled out at Sept national meeting. Negotiating with PubMed Central to put together umbrella policy.
(“The Public Access ship has sailed”)
- SPARC/NLM: Working as go-between for these efforts.

Questions I always get asked...

- How did I get my organization on board?

It was easy - it seemed “obvious” for an advocacy org so I had literally zero pushback from board

- Was I worried about “restricting” grantees?

Absolutely, but Pubmed Central team rapidly convinced me there was no need to worry

- How did researchers react?

Only feedback was positive (NIH and HHMI policies helped)

- What was the budgetary impact?

None

Some Worrisome Equivalencies:

Public/Open Access Policies =

= Require publishing in “open access” journals

= Inability to publish in journals with high impact factor

= Place unfair onus on grantees

But last year...

A Whiff Of Change in the Air!

contacted by two biomedical non-profits early 2010

Testimony to Congress July 2010

Invited to speak at variety of 'OA week' events Oct 2010

HRA invited me to provide webinar Nov 2010

Rockefeller Funder's Workshop April 2011