

Tonight I viewed a webinar presented by DS Achieves (DSA - www.dsachieves.org) - a relatively new organization dedicated to research, advocacy, and education related to Down syndrome. The presentation was given by the Founder and CEO of DSA, Lito Ramirez, who is the father of a child with DS and who has a great deal of professional experience in the areas of advocacy, government, public policy, and health care. It was upsetting, thought provoking, and motivating.

The presentation focused on the history of DS research, comparisons between research dollars spent and strides made related to DS and other conditions (particularly CF and autism), and a description of what DSA hopes to achieve. Here's the gist:

- * Despite DS being a relatively high incidence condition, it receives disproportionately lower funding from the feds compared to other conditions
- * None of the "major" DS associations focus on research advocacy -- they either do just research (with private \$), education, awareness, or advocacy for other topics (like education, social issues)
- * There's a direct correlation between advocacy dollars spent and federal funding received (SHOCKER, I know!)
- * As a result, the great strides we've seen with other conditions just haven't been realized for DS - we are essentially still in the "mouse model" phase of research - which is ridiculous considering how long ago it was recognized and the chromosomal abnormalities were identified

Lito was an effective and inspiring presenter - clearly passionate about this work - and overall, it definitely made me want to get more involved. But that's where it gets a little complicated - for me, anyway.

My personal political beliefs are such that I don't think the federal government should be the primary source of research funding for medical conditions. Yeah, I know where I work and see how that could be construed as hypocrisy LOL. I CLEARLY believe in the public health mission (or I wouldn't have gotten my MPH to begin with) - I just often find it's been taken way too far. Mission creep, if you will. It's why Brian and I give money directly to DSRTF to fund DS research - no govt agency needed!

But, to date, legislators and presidents have disagreed. We pour GOBS of money into medical research. Some for high incidence, high morbidity conditions, some for low prevalence, low morbidity conditions, and everything in between. What I think we can all agree on is that it's the

conditions with the loudest voice (or that affect members of Congress and their families) that get funded. I'll refrain from providing specific examples from my job, lest I become inappropriate LOL.

So I have my personal political leaning, but then I figure - well if the feds are handing out research dollars, then DS deserves its share. Cuz we sure as hell aren't getting them now. (And really, bravo to the groups who lobby successfully for funding...I don't begrudge them their dollars; I am just disappointed DS has been woefully silent and ignored.)

That's the short answer of why DS scientific research has fallen short -- we have no advocacy group demanding that this work be done. NDSS and NDSC do some lobbying, but it's largely around social issues or education. DSRTF does the good research, but they don't have an advocacy arm. Other groups fall into one of those 2 categories too. This was discussed at length in the presentation, and described really well, I think.

But I think there's a longer answer that we need to acknowledge and talk about - because it's going to affect our ability to come together as a community to do the effective advocacy that we need in order to see results. And that's about how our kids have been viewed historically, and how we view things today. Perception is reality, right?

It's my belief that, historically, DS (and lots of other conditions affecting cognition) was just seen as "not fixable." Like it's not a medical condition (physical health issues aside -- those have been treated differently) - it's just how they are. And we had a host of words to describe people with cognitive delays or disabilities....retards, idiots, imbeciles, etc. They were treated as lower class citizens and not valued b/c they had limitations on their ability to participate fully in the community. So it's easy to ignore them, ignore their needs. Anyone who's ever been to an IEP meeting or sat in on budget discussions regarding special education knows that this sentiment is not entirely gone. How many budgets are balanced on the back of the kids with special health care needs? People with disabilities of all kinds have been disenfranchised for an eternity in systematic and painful ways.

And then there's where we are today, as parents. In my experience, I've met parents who fall into different camps: those who are on board with research to enhance the cognitive abilities and improve medical conditions of people with DS, those who are not, those who are somewhere in the middle depending on the type of research you're talking about, and those who do not have the luxury to worry about such things because they care for medically fragile children and are

focused on just keeping them alive each day (I'm not being flip here...I really can't pretend to know what you are going through and my heart is with you...)

I am not judging any one on any aspect of that spectrum - just stating I think there's a spectrum! And, from what I've heard from friends (and discussed with them at length), there is a lot of fear of research -- the experiment of it, the worry that it will "change" our kids, and the concern that treating aspects of DS means we somehow don't accept our kids how they are. People are entitled to those feelings, and have good reasons for them. But I think we need to acknowledge this as a community if we're going to make a difference. I don't think we can take for granted the various viewpoints of parents and family members...we do not have common experiences or share one voice.

I think DS still has a lot against it when it comes to convincing people that research will help. I think it's why it's 2011 and we don't have a national, strategic advocacy plan (but I'm positive DSA will change this). But if we don't believe in this as a community, legislators and funders won't either.

As it happens, and if you haven't been reading carefully (this is rather long), I fall into the "hell yes" research camp LOL.

I love Emlyn to the moon and back. I couldn't love her more. I will do anything and everything in my power to make her life better and allow her to participate as fully in our community as she is able. She goes to school. We do therapy. We play. We are vigilant for medical problems. We take her everywhere to expose her to the world, and the world to her. We love her. And I think supporting research is a big part of the equation, too.

DSRTF has made great strides with mouse models. I fully believe they will be able to positively affect cognitive ability in people with DS, in Emlyn's lifetime. I really do. Would I give Emlyn that opportunity if it became available? You better believe it. If something can help her think more clearly, communicate more effectively, and be more independent, she's gonna have it. Not b/c I need my kid to be a DS "superstar"...Emlyn needs to be who she is. But I truly believe making these types of changes does NOT fundamentally change who she is. If my kid has plaque in her brain affecting the ability of neurons to communicate - then get rid of the damn plaque! Or whatever! Just like I'd want to fix her heart or her kidneys or her arm if it was broken. It's the same to me.

I am super excited about the work of DSA. I believe they have the talent and expertise to help move our community along, and I really hope enough parents fall into the "research positive" camp because this REQUIRES a singular, loud voice. We need lots and lots of people to not be complacent and to see the potential here if we're going to be successful.

Hmph. Wonder if DSA is hiring? LOL