

Oral Public Comments

**IACC Full Committee
Meeting**

July 26, 2017

List of Oral Public Comments

Thomas Frazier, PhD.....	3
Carol S. Weinman, Esq.....	5
Mary Jo Lang, PhD, PNP, BCBA-D	6
Margaret Gautier.....	7

Thank you to the IACC committee for the opportunity to present an update on Autism Speaks science activities and future directions.

MSSNG

As the world's largest autism whole genome sequencing project, the Autism Speaks-funded MSSNG program complements NIH and Simons Foundation exome and targeted sequencing efforts. Over 100 investigators from more than 30 institutions and 8 countries are currently accessing more than 5,000 sequences that we've made available in an open-science fashion through an easy-to-use web-based interface on the Google Cloud. We expect to release an additional 2,200 sequences in the coming months, followed by the rollout of the MSSNG community portal. The community portal will allow families participating in MSSNG to obtain the results of their whole genome sequence, access genetic counseling, and connect with other families with similar genetic findings.

To date research on the MSSNG genomes has identified 61 autism risk genes, including 18 genes that had not been previously strongly established. Most of the identified risk genes clustered into 3 biologically distinct pathways, supporting the potential for identifying personalized pathway-based therapeutic strategies. Importantly, we see MSSNG as providing a very important complement to exome sequencing efforts by providing the capacity to interrogate the role of regulatory DNA in the biology of autism.

Autism Treatment Network (ATN)

The Autism Treatment Network (ATN) is a collaboration of 13 clinical research sites located in leading academic medical centers across the US and Canada. It is two closely inter-related networks with the ATN funded via Autism Speaks and the Autism Intervention Research – Physical Health (AIR-P) network funded by HRSA. Since its inception, the ATN has been a leader in clinical care improvement, including the development of toolkits, carepaths, medical guidelines, and training of medical providers.

Major accomplishments include the voluntary participation of more than 7,000 patients in a phenotypic registry that provides detailed information regarding autism symptoms and co-occurring mental health and medical conditions. More than 100 peer-reviewed publications have been generated via the ATN registry and additional ATN/AIR-P studies.

Families, individuals and medical professionals have downloaded ATN toolkits more than 230,000 times, and we've provided more than 15, 000 thumb drives to medical providers. Since 2012, five medical guidelines for ASD have been published in Pediatrics. In 2016 alone, the ATN has provided training to more than 1,300 providers and care coordination to more than 16,000 families.

In the future, we anticipate that the ATN may play an even more powerful role as a learning health network able to conduct clinical trials of personalized therapeutic strategies as well as treatments and products currently being used by families without strong evidence.

Weatherstone Fellowships

The Weatherstone pre-doctoral fellowship program is in its ninth year with 63 total fellows with a class of 8 fellows expected later this year. Our fellows have been incredibly successful in developing research careers in autism, and many have grown into innovators and leaders in the field. Fellow blogs have been a beneficial resource for explaining their research and its impact on individuals and families affected by autism.

Strategic Planning for Autism Speaks Science

The Autism Speaks science team is engaged in a strategic planning process focused on developing a 3-year plan for driving autism science forward. As part of the process we have been receiving feedback from the full range of stakeholders through our Science Survey.

The survey includes 13 questions (including open-ended responses) that gauge what stakeholder groups perceive as the most critical directions and topics for Autism Speaks support. As of July 5, we have received more than 4,800 responses with rich feedback and thoughts about important directions.

In aggregate, initial findings suggest that respondents see both basic and applied science as important with an edge toward applied science. In general, respondents felt that lifespan, adult transition, health/well-being, behavioral and social interventions, and medical interventions were most crucial. Ratings and comments emphasized the importance of disseminating and implementing interventions. Understanding the causes, underlying biology, and measurement of autism – while less critical – were still rated as important. Most importantly, we plan to analyze the full results after additional data are collected and to present results by the respondent's relationship to autism.

We anticipate continuing to broadly address the discovery, translation, and solution spaces while focusing more on pre-clinical and clinical trials that test and advance interventions that can make a substantial difference in the lives of individuals with autism.

Summary

While we await the survey results and completion of strategic planning, we can say that AS science sees itself as having an important role in driving the field forward by seeding novel projects, collaborating and complementing other funders, contributing to the development of the next generation of scientists, focusing on implementing and disseminating solutions for individuals and families, and connecting research findings to the community.

Individuals who are interested in participating in the Autism Speaks Science Survey can use the following link:

<https://www.surveymonkey.com/r/J6H2K3L>

Thanks!

Note: Personally Identifiable Information (PII) has been redacted in this document

Carol S. Weinman, Esq

July 26, 2017

I am Carol Weinman, an attorney, certified autism specialist, international speaker and mother of a son with autism. While much attention is given to the victimization of those with ASD, my work focuses on those with ASD who are characterized as criminal offenders.

One in 68 individuals is on the autism spectrum and 1 in 45 is male. Of those, a high percentage, ages 13 and up, are experiencing encounters with law enforcement and the criminal justice system. That is why the growing concern of autism and crime is a topic of relevance in discussions on Transition. Most often these so-called perpetrators are those on the high functioning end of the autism spectrum. This presents a compelling need to determine why it is happening and what needs to be done to prevent the escalating numbers. The primary means of prevention are education and training of those in law enforcement and the criminal justice system. Training police officers what to look for, how to approach these individuals and what to do is a key component in preventing what could become a criminal matter from progressing further within the criminal justice system. Educating prosecutors, attorneys, judges and probation officers prevents the often unjust and inappropriate treatment of this misunderstood and vulnerable population. Many among this population – who are already facing numerous life challenges – are adding to that a criminal record and listing on a sex offender registry. In an effort to prevent escalating criminal arrests, my primary focus is on demystifying the behaviors that are often misinterpreted as suspect and socially inappropriate. It is imperative to raise awareness of this issue and to increase the understanding of why it is happening, what needs to be done to prevent it, and what can be done to improve treatment and rehabilitation of those convicted or imprisoned. Additionally, certain child pornography laws and mandatory penalties need to be reassessed to consider their efficacy and sense of justice when involving the viewing, downloading and distributing by those with ASD.

Carol S. Weinman, Esq.
Weinman Law Office
[PII redacted]
Fort Washington, PA [PII redacted]

1. Due to the complex nature of the autism disorder, parents experience a high degree of stress and trauma. One example is supported by a high degree of divorce rates. Mental health services are critical to the individual with autism as well as their family. I would like to see more mental health services available to these families.

2. I'm concerned about the budgetary cuts proposed by the current administration regarding funding for individuals for autism such as Medicare. We need to advocate for increases for funding for individuals impacted with autism and their family.

3. At the last International Society for Autism Research Conference in San Francisco, the majority of the research focused on high functioning, verbal, employable individuals with autism. There needs to be more research focusing on individuals that have moderate to severe autism. The intent of research should be to identify interventions to facilitate these individuals' quality-of-life and positive contributions to society.

As a parent, what I see is an array of issues within my community regarding Autism. Firstly, Autism should be federally recognized as a speciality that requires some type of certification and accreditation in an effort to administer consistent educational services across the nation. Leaving it up to the states does not provide consistency in educational standards, quality control of teachers, or a transparency of understanding for parents who are still learning about Autism, yet alone their rights or the availability of services and support within the school system which is exactly what I am experiencing now. The teacher of my student has not assessed him informally the entire year or contributed instructional direction to his academic goals in any way which has resulted in one year of lost instructional learning. This is a typical caveat of not having this condition as a federally accredited or certified specialty. Functional curriculums have not been formally adopted which leaves teachers inventing the wheel for each and every child for the duration of their employment or students enrollment. With the array of behavioral components that surround this condition, the various levels of learning and so forth, there needs to be a way to bridge the gap between the scientific communities and the other communities that are administering services by standardizing autism as a speciality governed by an accredited body of some sort. Teachers, therapists, and other specialists should be able to receive a certification by a federally approved program to administer services to students to help with quality control. Someone who is ABA certified doesn't necessarily have the training or experience to help treat autism students or patients as the case is in my county. Just because a teacher has 5 years of special education experience, doesn't mean they know how to or want to administer services properly for an Autistic child like what I am currently experiencing. OT specialist or speech therapist who administer services in counties or states should have specialized autism training and have this speciality as a part of their credentials from a certified program that is accredited by the federal government or their state just like other standards are such as the amount of hours of instructional learning being a part of DOE accreditations. Functional learning curriculums should be able to help teachers determine the grade level of functionality a child is performing at. Based on my current experiences, my state has a VAAP but it does not indicate what grade level of functionality my student is placed in, i.e. 1st, 2nd 3rd grade etc., only that he passed it. This does not help me to help him at home because most parents do not understand what this is for due to poor communication from the state and county. Eligibility or Evaluations are done every 3 years in Va and each year corresponding until the next 3 year mark, the teacher and IEP team is responsible for providing instructional learning which helps shape the IEP. Unfortunately, the IEP is only as good as the team. My current team is not cohesive, the teacher has not demonstrated the willingness to conduct informal assessments in an effort to guide my child's academic growth. These are the common issues that plague the Autism Community. Issues like this can cause regression and because their growth has been hindered. This will continue to happen if certain practices are not mandated. Assessments both formal and informal, need to happen more often because there are many children that benefit from these especially if the parents are uneducated or still learning about Autism who seek guidance from professionals to help them help their child. Virginia resources are so scattered and it makes accessibility difficult when students are required to fill a specific amount of instructional time. Special education department's should start having an autism cluster or subdivision so that they can focus solely on autism services. My state and PWCS have no such thing. If this subdivision was created, then it can help educators and other specialists to tap into other resources such as the IACC to help guide their counties or states. People that are here and placed in the higher level positions to represent the state or counties are not made visible until parents seek out and hopefully stumble across the right person(s) to help them. Educational standards for autism need to be changed and made more consistent to help bring about more functional individuals and consistent educational standards. Resources for parents aren't always made apparent and because of that, parents are frustrated and left unresolved because they

spend countless hours trying to help themselves and do not always know what to look for. These are just a few things that I wanted to share and hopefully there is something good that comes of this. Thank you for your time. Please let me know how I can help this effort.

In summary, my comment concerns the public school system and the need to provide more support, information and methodologies to help support and improve Autism as a service in the school systems. My child has experienced inconsistent levels of education because schools systems have not been able to adopt a functional academic curriculum, place students in the appropriate learning environment that properly supports a progressive functional academic path, or have a way of identifying students level of proficiency. There also should be an increased use of technology for these type of students and I believe that this can help to drastically impact Autism in a positive way because it would allow them to develop without the complications of personal interactions that are difficult for them to process.