



**U.S. House of Representatives  
Committee on Oversight and Government Reform  
“1 in 88 Children:  
A Look into the Federal Response to the Rising Rates of Autism”**

**Hearing Date: November 29, 2012**

**Statement of the National Autism Association New York Metro Chapter**

Chairman Issa, Ranking Member Cummings, and Members of the Committee:

The National Autism Association New York Metro Chapter (NAA NYM) wishes to thank you for holding the November 29, 2012 hearing on the federal response to the rising autism rate. While the November 29 hearing was an auspicious start, we urge the Committee to continue to further investigate autism. In particular, we urge you to hold further hearings on critical issues with respect to autism in the near future.

**National Autism Association New York Metro Chapter**

Founded in 2008, NAA NYM is an all-volunteer organization serving the five boroughs of New York City and the following counties: Westchester, Rockland, Suffolk and Nassau. We are led by parents and grandparents of children with autism and professionals who have dedicated their lives to helping people with autism reach their fullest potential. We provide to individuals with autism spectrum disorders and their families, caregivers, and professionals who work with them educational meetings, support groups and mentors, workshops, sports activities, and a summer program. We advocate for people with autism to give a voice to the many who cannot speak for themselves.

**What We Ask Of You**

As Chairman Issa recognized, the November 29 hearing hopefully was the start of many more hearings addressing critical issues relating to autism. NAA NYM urges the Committee to hold hearings on and to investigate:

- ***The vaccine-autism connection.*** The science is incomplete on this issue and, in particular, a study of health outcomes comparing vaccinated and unvaccinated populations must be done. Dr. Colleen Boyle admitted to the Committee that this critical research has never been done by the Centers for Disease Control. Supporting the need for further research concerning the

vaccine-autism connection is an article authored by Mary Holland, Louis Conte, Robert Krakow and Lisa Colin titled *Unanswered Questions from the Vaccine Injury Compensation Program: A Review of Compensated Cases of Vaccine-Induced Brain Injury*, Pace Environmental Law Review, vol. 28, no. 2, 2011

(<http://digitalcommons.pace.edu/cgi/viewcontent.cgi?article=1681&context=pehr>). This article brings to light that, since 1989, the Vaccine Injury Compensation Program (VICP) has been compensating cases of vaccine-induced brain injury associated with autism. Using publicly available sources, the authors of this article showed that in seventeen published decisions, Special Masters overseeing cases in the VICP described autism as a possible consequence of vaccine injury. Moreover, the authors found 83 cases of autism associated with compensated claims of vaccine injury, in both published and unpublished cases. There likely are many more cases. Additional studies of both of the scientific issues concerning vaccines and autism as well as issues concerning the compensation program need to be undertaken;

- ***Vaccine research.*** Further research must be done with respect to the extraordinarily packed vaccination schedule, including research regarding the inadequacy of vaccine safety testing generally and, critically, the failure to safety test vaccines as administered “in real life.” We urge you to look into the fact that multiple vaccines are often recommended in a single visit to the doctor but are not safety tested that way. Moreover, the entire vaccine schedule as administered has never been safety tested. We also urge you to examine the vaccine research, testing, and approval processes for conflicts of interest which may result in flawed decision making based on interests other than public or individual health;
- ***Research into other environmental agents that may trigger autism.*** It is clear that autism is not an entirely genetic disease. Autism rates have increased precipitously in the last 20 or so years and there is no such thing as a genetic epidemic. Rather, autism is a disease in which those who are genetically susceptible succumb to an environmental trigger or triggers. Genetic research has yielded few clues to autism despite millions of dollars and many years spent focused on genetics. We need a better way to identify those who are susceptible and we need to identify the environmental toxins that can trigger autism;
- ***Research into the serious health conditions often faced by those with autism.*** Individuals with autism frequently have other very serious medical conditions, including mitochondrial disease and dysfunction, gastrointestinal diseases, seizure disorders, immune system disorders, and others. Research into the connection between these conditions and autism must continue. Moreover, medical professionals must learn to recognize those conditions in individuals with autism and to provide appropriate care;
- ***The Vaccine Injury Compensation Program.*** As Representative Burton pointed out, the VICP does not function in the way it was intended to and many injured by vaccines never receive compensation. Others fight for years in what was supposed to be a forum to quickly adjudicate claims, and many families are treated shamefully in the process. Future hearings could draw attention to the serious flaws in the program and examine if and how the program could be reformed. Moreover, we urge you to investigate what officials at the VICP itself, as well as officials at the U.S. Department of Health and Human Services and the U.S. Department of Justice, knew about the vaccine-autism connection and when they obtained that information, as well as to further investigate compensated VICP cases with

respect to an association between vaccine-induced brain injury (or other injuries) and autism;

- ***Educational, employment and care services.*** For many on the autism spectrum, the need for lifelong services is a reality. At one end of the spectrum, services may be educational supports in a mainstream setting and job placement and workplace supports. At the other end of the spectrum, services may include twenty-four hour care such as toileting, protection from wandering-related injury or death, and protection from self-injurious behaviors. In between, there are many people with autism needing a variety of supports. Much as we need research into causation and prevention, we cannot forget the current and future needs of those individuals already diagnosed with autism spectrum disorders. As the first wave of the autism epidemic now is aging out of the educational system, those needs will increase and the government must have a comprehensive, coordinated plan to address this issue.

### **The Government's Response to Autism Fails to Confront the Epidemic**

Retiring Representative Dan Burton began asking crucial questions concerning autism over a decade ago and last week's hearing once again put the spotlight on autism. In the decade since the autism hearings held by Representative Burton and his Committee, it has become clear that the federal government – particularly the Centers for Disease Control and the National Institutes of Health – lacks a sense of urgency concerning autism. The federal government has not mustered leadership to address this increasingly significant health, education, and services emergency. The Inter-Agency Autism Coordinating Committee (IACC) is a prime example of the government's failures with respect to autism. The IACC simply is not a leader with respect to autism and its response to the autism epidemic is disappointing, particularly with regard to causation and to issues that impact the many people with autism who are severely affected, including those who have multiple autism-related medical conditions. As the Committee clearly recognized, federal agencies lack a sound and coordinated national strategic plan concerning the autism crisis at a time when a coordinated plan with measurable goals and time frames to achieve those goals is greatly needed.

Participating Committee Members and other attending Representatives justifiably were alarmed that the autism rate has soared to 1 in 88 children (and even that figure is based on children born in 2000). In sharp contrast, the government's witnesses, Drs. Colleen Boyle and Alan Guttmacher, representing the CDC and NIH, respectively, refused to recognize autism as the epidemic and true national emergency that it has become. As their testimony demonstrated, these governmental entities appear disinterested in changing the *status quo* with regard to their response to the autism epidemic. Highlighting the IACC's tepid response to the autism crisis, the IACC's Chairman, Dr. Thomas Insel, failed to appear at the November 29 hearing.

During the hearing, we saw the Committee repeatedly try to elicit clear and direct answers from Drs. Boyle and Guttmacher, and we share with those Representatives the impatience and frustration that many of Dr. Boyle's and Dr. Guttmacher's responses engendered. Their often elliptical responses to your straightforward questions only further demonstrated the lack of a coordinated and urgent response by their agencies to the autism epidemic.

## **The Status Quo Must Be Challenged**

The *status quo* must be challenged with respect to autism, the cost of not doing so is too high. If the tide of autism is not stemmed, the effects on this nation's economy will be devastating. For this reason, research into all possible causes of autism cannot be ignored any longer. Moreover, research must be done concerning autism and the myriad of serious medical conditions that often accompany autism. For those already struggling with autism, whether they are mildly or severely impacted, a continuum of appropriate educational, therapeutic, and support services must be provided. Appropriate services will allow each person with autism to achieve their highest potential. The earlier appropriate support is provided the better, but we must never give up on anyone. While support services are costly, the long-term impact of failing to provide those supports is even higher. Without support, many with autism will never work, never pay taxes, and will be denied the opportunity to participate as fully in life as they could with assistance.

NAA NYM is profoundly grateful to the Committee for holding this hearing and we appreciate the Committee's willingness to ask tough questions and to not shy away from critical issues concerning autism. Autism does not discriminate along political party lines and NAA NYM applauds the bipartisan nature of the hearing. We wholeheartedly agree with the Committee that the time has come to hold the government accountable for what can only be described as a national health crisis.

There still is much to be learned and much work to be done on the complex issues involved with autism but on November 29, 2012, you gave us – and the many thousands of families who daily struggle with the challenges of autism – hope that important truths about autism and the government's response to the autism epidemic will be revealed and that the autism epidemic will receive the attention it deserves and desperately needs.

NAA NYM is available to assist the Committee in any way it can.

Respectfully submitted,



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December 6, 2012