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Combating Autism

U.S. Rep. Chris Smith (NJ-04)
Co-Founder & Co-Chairman
Congressional Coalition on Autism Research and Education
(C.A.R.E.)

Autism New Jersey
32nd Annual Conference
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Thank you Autism New Jersey for so effectively advancing the welfare and wellbeing of people with ASD and for providing hope and expert insight to persons with ASD, parents, family, policy makers and the public.

Autism New Jersey is blessed with highly dedicated, smart and tenacious leaders including and especially Dr. Suzanne Buchanan.

Autism New Jersey has made an enormous difference for decades. Working with New Jersey Assembly Speaker Roberts, Autism New Jersey helped enact historic health insurance coverage in 2009 and you've rallied behind every autism law I've sponsored over the past 17 years.

When I first got elected to Congress in 1980, the generally accepted prevalence rate for autism in America was approximately 3 in 10,000.

Today it's 1 in 68; 1 in 45 in New Jersey. I've chaired three congressional hearings on global autism—no nation is immune.

I was supportive of Autism policy since a visit to a group home run by Eden Institute of Princeton in 1981 but remained mostly on the margins until 1997 when two wonderful parents of children with autism—Bobbie and Billy Gallagher, one of whom is here today (Bobbie)—conducted a comprehensive audit and asked that I look into an apparent prevalence spike in autism in Brick Township in neighboring Ocean County. Working closely with the Gallaghers I invited the CDC and other agencies to Brick to investigate.

Not only did the CDC probe suggest that Brick's autism rate was higher than previously thought, but the data calls to nearby municipalities revealed disturbingly high numbers there as well.

So in 1999, again working with the Gallaghers, I introduced the Autism Statistics, Surveillance, Research and Epidemiology Act (ASSURE) to establish autism centers of excellence and to create the first interagency autism coordinating committee.

For the next two years, parents and advocates in this room played a pivotal role—against significant opposition—in securing enactment of the ASSURE Act, in its entirety, as Title I of the Children’s Health Act of 2000.

Since then, we have made serious progress. The Interagency Autism Coordinating Committee (IACC) Strategic Plan notes that “with major findings emerging nearly every week, autism research has become one of the hottest fields in biomedical science.”

Work on early screening tools has accelerated and that’s good, but only 20 percent of children are being identified early—and that’s not good—by three years of age. That needs to improve.

Not getting early diagnosis means those kids aren’t benefiting from early intervention.

According to IACC research on the potential relationship between the immune system and ASD has grown considerably over the past two years, resulting in several major breakthroughs... .”

The role the immune system plays in ASD is finally coming under more intense scrutiny.

This area of inquiry begs the question as to antibiotic overuse and whether or not probiotics might be helpful.

Antibiotics not only destroy the bad bacteria in our intestines but decimate the good gut flora as well—which is a critical component of a healthy robust immune system. According to IACC, the microbiome consortium has provided important insights into the role that microbes might be playing in many human conditions, including ASD.

The IACC also noted a “landmark” study of the molecules and cellular underpinnings of autism by using adult stem cells—specifically pluripotent stem cells—from skin cells of two people with Timothy syndrome.

While I have no intention of conveying false hope or unrealistic expectations, I am encouraged that according to NIH’s clinical trials at least seven trials are probing the safety and efficacy of umbilical cord blood and/or bone marrow stem cell research for autism. I am particularly interested in this since I authored the Stem Cell Therapeutic and Research Act of 2005 (Public Law 109-129) that created the federal cord blood/bone marrow stem cell program.

As you may know, the largest number of studies to date have addressed increased ASD risk with air pollution exposure during gestation and/or early infancy. Multiple studies have found significant associations. There is also suggestive evidence that chemicals such as pesticides may be associated with ASD.

“Particularly intriguing” the IACC writes, “are the results of prenatal vitamin intake through supplements and diet, showing a 40% reduction in risk of ASD with prenatal supplementation taken in the three months before or during the first month of pregnancy, but not during pregnancy months 2-9.” The 40 percent reduction in risk for women who used folic acid supplements in the time around conception was replicated in a large Norwegian study.

Finally—and as you all know so well—every level of government, local, state and federal, is woefully unprepared for the estimated 50,000 children with ASD who annually graduate from their high school-based support system and age-out.

For years I've introduced bipartisan autism services legislation with Democrat Congressman Mike Doyle of Pennsylvania that has gone nowhere. It's clear now that we must establish an evidence-based comprehensive blueprint—an action plan if you will—to muster the votes in Congress for the necessary resources.

So this year, when I introduced the \$1.3 billion Autism Collaboration, Accountability, Research, Education and Support (CARES) Act which was signed into law on August 7, we included a major requirement that the Secretary of Health and Human Services along with the Secretaries of Education, Transportation, Labor, Housing and Urban Development and the Attorney General study, analyze and report back to Congress on:

- demographic characteristics of youth transitioning from school-based to community-based supports all policies and programs relevant to young adults with ASD relating to post-secondary school transitional services;
- proposals on establishing best practices to ensure interdisciplinary coordination between all service providers receiving Federal funding;
- comprehensive approaches to transitioning from school-based services to those services available during adulthood including post-secondary education, employment, behavioral supports, housing, transportation, nutrition, health, recreational and social activities
- and personal safety services related to public safety agencies and the criminal justice system.

We will get the report on these.

A few months ago I chaired a congressional hearing on the challenges of aging-out including employment opportunities. Jose Velasco of SAP—the global software giant—testified that SAP believes there is a “strong affinity between the natural ways of our colleagues on the spectrum and software development and IT. There is real opportunity” he said “to leverage the skills of people with autism in the workplace.” By 2020, SAP hopes that at least 1 percent of all SAP employees will be represented by people on the spectrum. They are truly pioneers and innovators. Jose also testified that more than 15 other companies are interested in implementing similar programs.

Jonathan Kratchman is a remarkable young Hamilton Township student with ASD. He wrote and delivered an inspiring speech that he gave at Mercer County Community College last year at the Dare to Dream conference. He said: “Here’s a fast fact. If you take your high school diploma at age 18, you automatically lose services from your school district. I know,” he went on, “I can be a great contributor to society when I graduate. However, I need continuing support to get there.”

Continuing support for Jonathan—and all children and adults on the spectrum— to “get there”? Absolutely. Again I say absolutely.