



**AUTISM
POLICY
REFORM
COALITION**

April 8, 2018

Dear Congressmen and Congresswomen,

Once considered a rare and incurable condition, the incidence of autism has skyrocketed in this country over the last two decades. The Autism Policy Reform Coalition (APRC) has constituted itself as organizations in service of people with autism who are coming together from every district across the U.S. for the purpose of proposing meaningful legislation reforms that will make a real difference in the lives of those with Autism – their families, physicians, communities, and our nation.

Autism is a spectrum disorder. There *are* high-functioning types contributing to society, but approximately one-third of people with autism are severely disabled by it: many are non-verbal and have co-morbid medical conditions like gastro-intestinal disease, seizures and metabolic dysfunction. Autism costs families and taxpayers dearly. But there is hope and progress being made along the developmental spectrum as novel therapies emerge and committed families work to help these severely affected children succeed.

Despite legislation passed starting in 2006 which authorized the creation of the Interagency Autism Coordinating Committee or “IACC” in order to coordinate autism policy and research across federal agencies, and valiant efforts on the part of individual committee members, 12 years later, very little progress has been made. Approximately \$1.6 billion has been spent to date with no real gain in understanding or recognition of the types of autisms that exist, the causes, best treatments, or means of deterring potential environmental triggers for children who are developing normally and regress. The IACC meets several times a year for one day. The head of the IACC has other responsibilities in NIH and the IACC reports to no one. There is no mechanism to assess the effectiveness of the strategic plan or even whether the strategic plan is being followed.

Today, there are 30% MORE 12-year-olds with autism than there were just two years ago. APRC is a proponent of government action with a sense of urgency toward:

- The creation of government structures to coordinate and guide strategy and funds related to Autism research and care.
- The creation of legislative mandates for environmental concerns.
- Input from community stakeholders.
- Medical models focused on quality clinical care and translation of research into standards of care for this special patient population.

Please help us achieve the reform we so desperately need! Go to www.autismpolicy.net to learn more.

Sincerely,

Dawn Loughborough

President, Autism Policy Reform Coalition