

Congress of the United States
Washington, DC 20515

November 19, 2015

The Honorable Shaun L.S. Donovan
Director
Office of Management and Budget
Washington, DC 20503

Dear Director Donovan:

We write to you today to request that you and your Administration colleagues include language in the President's Budget Request for Fiscal Year 2017 that will establish an initiative designed to achieve a goal of lowering the national average age of diagnosis for children with autism. We believe this kind of bold initiative will have a substantial beneficial impact on the quality of life for children and families affected by Autism Spectrum Disorder (ASD) and will also generate substantial savings for governments at all levels.

Efforts that would lower the current age of diagnosis from nearly four and a half years old to three years of age or younger would allow more children to receive early intervention services when they are most effective. If intervention and treatment can start earlier than previously thought possible, we could significantly improve the quality of life and long-term development of children with autism—permitting them to have more fulfilling and productive lives.

This goal is consistent with the objectives of the Interagency Autism Coordinating Committee to develop methods of detecting ASD before all the symptoms fully manifest themselves, and the language included in our bill, the "Autism Collaboration, Accountability, Research, Education, and Support Act of 2014," or the Autism CARES Act, Public Law 113-157. The House Energy and Commerce Committee report accompanying the Autism CARES Act stated in part:

"In implementing the programmatic and research initiatives funded by this Act, the Committee strongly encourages Federal agencies to pay particular attention to the need to focus on early diagnosis and intervention in children ages 5 or younger. With new advances in scientific research relating to autism, it is important that Federal agencies are aware of and taking into account that the average age of diagnosis could drop, in the very near term, from ages 4 and 5 to toddlers and younger. The Committee is aware that there is evidence-based science that will make it possible to identify signs of autism present in the first year or two of life, thereby opening a window for even earlier diagnosis and intervention in the future."

At this time, we are seeing exponential growth in the number of children diagnosed with ASD and significant strides in scientific research that permits earlier and earlier diagnoses and

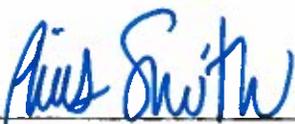
interventions. Using a variety of methods, researchers around the nation are focusing on earlier detection and intervention, with studies finding that some signs of autism are present already in the first two to six months of life. By some estimates, diagnosis and access to evidence-based early intervention could reduce the lifetime cost of autism by as much as two-thirds. The lifetime cost for an individual averages \$2.4 million when autism involves intellectual disability and \$1.4 million when it does not. An estimated 40 percent of individuals with autism also have intellectual disability. Based on these numbers, the yearly cost to the United States is an estimated \$236 billion a year. Thus, we believe that there is a value proposition inherent in emphasizing research and programs that will lead to the earliest possible diagnosis and intervention.

We believe that a government-wide review of federal programs would show numerous examples of how small changes to existing programs that would ensure a focus on early intervention could help achieve this goal. In addition to biomedical research, existing programs within the Departments of Health and Human Services, Education and Defense are ideally suited to provide early diagnosis and intervention.

If health care and education providers can identify children early and provide evidence-based interventions, we can save many children from a lifetime of support. This is a good use of our resources, as it will ultimately reduce the cost of services needed to support these children and their families for years to come. Including a stated goal of lowering the average age of ASD diagnosis in the FY17 budget would take a critical step toward ensuring that funding and policies take into account this important societal issue.

Thank you for considering our request and we look forward to continuing to work with you to ensure that all those affected by autism have access to the research and services that assist in long-term development.

Sincerely,



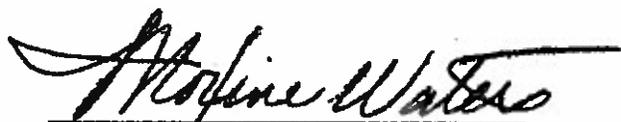
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Co-Chair
Congressional Coalition for Autism
Research and Education



Mike Doyle
Co-Chair
Congressional Coalition for Autism
Research and Education



Peter King
Member of Congress



Maxine Waters
Member of Congress



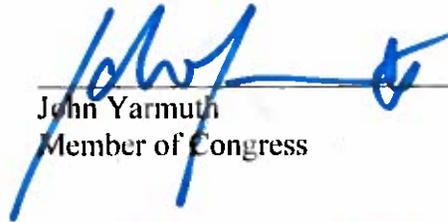
Ted Deutch
Member of Congress



David Scott
Member of Congress



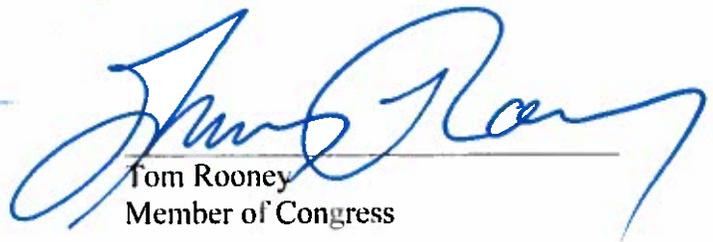
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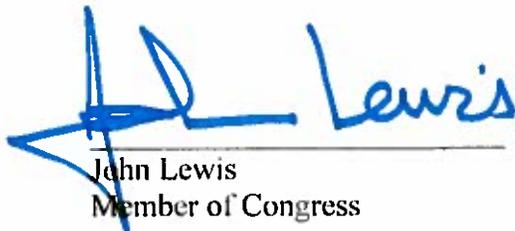
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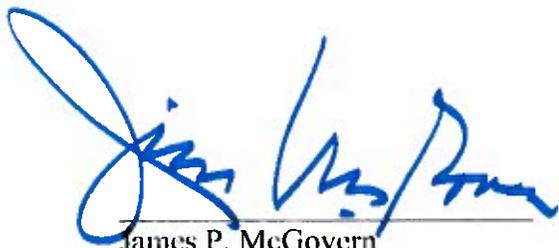
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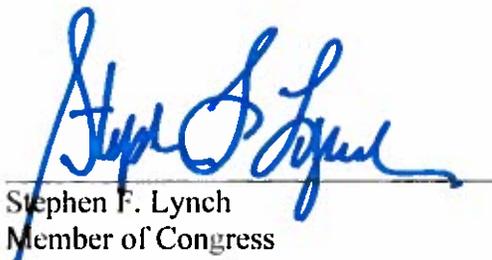
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Ann McLane Kuster
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Stephen F. Lynch
Member of Congress

cc: The Honorable Sylvia Burwell, Secretary of Health and Human Resources
The Honorable Arne Duncan, Secretary of Education