**Sample email text requesting Congressional DC appointment:**

Subject: Meeting Request Congressman XXX (Can use specific subject lines to quickly identify who is replying)

(Dear XXX)

I am writing to a request a meeting with Congressman XXX on Wednesday March 6, 2019 to discuss federal funding for research into discovering a cure for tuberous sclerosis complex (TSC). If Congressman XXX is unavailable I am more than happy to meet with the legislative aide handling Defense health programs. (Last year I met with XXX)

My (son/daughter/myself) has this genetic disorder. and … [briefly explain your current situation]

I am representing all the families in (state) affected by the disorder and will be scheduling multiple meetings. Thank you so much for considering my request. I look forward to hearing from you soon.

Sincerely,

Name

Phone

Email

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TSC is characterized by seizures and tumor growth in vital organs such as the brain, heart, kidneys, lungs and skin. Individuals with TSC commonly begin having seizures during the first year of life. These seizures, as well as brain tumors, contribute to cognitive impairment, including learning disabilities, behavioral disorders and severe intellectual disability. As you might imagine, the toll on the family of a person with TSC is enormous. Every day two children in the United States are born with this terrible disease. Nevertheless, TSC is considered rare and there is no cure.

Research conducted through the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense (DoD) is essential to develop treatments and eventually find a cure for the more than 50,000 Americans who have tuberous sclerosis complex. By making this investment now, hundreds of thousands of dollars are saved on a lifetime of care. In addition, because TSC is the leading genetic cause of epilepsy and autism, every dollar raised to find a cure and better treatments for TSC can also mean a better understanding of epilepsy and autism. TSC is also being used as a model system to study new cancer treatments. Of course, these devastating diseases touch the lives of all our friends, family and coworkers.

The TSCRP was launched in FY2002 and funded by Congress with an appropriation of $1 million. It has continued since, with an appropriation of $6 million in FY2017. While those initial investments represent important steps in advancing scientific knowledge about TSC, more is required if we hope to find ways to cure or prevent TSC from affecting more Americans.

The Tuberous Sclerosis Alliance is the only national voluntary health organization dedicated to finding a cure for tuberous sclerosis complex while improving the lives of those affected. **I will be joining other volunteer community leaders from around the country in Washington, DC on March 7, 2018.** **I would be grateful if the Congressman or staff could find some time to meet with me to discuss the Tuberous Sclerosis Complex Research Program funding.**