

# Meeting Request Letter

Meeting Request Letter (House)

[DATE]

The Honorable [Pete Sessions]

[1514 Longworth House Office Building]

Washington, DC 20515

Dear [Representative Sessions]:

I am writing to request a meeting with you in your district office in \_\_\_\_[name location]\_\_ during the July Congressional district work period. In particular, I am requesting the meeting with you to discuss a very important and personal matter — funding for research and activities to increase awareness of Rett syndrome. [If you will be bringing others with you mention that here]. My daughter, [name], has Rett syndrome, a rare and debilitating neurological disorder that was masked in our daughter until she was [age of onset of RTT in your daughter], when she went from a happy, typically developing child to one that is severely disabled, incapable of the smallest acts of independent daily living and unable to tell us her simplest needs.

Twenty years ago, no one had heard of Rett syndrome and parents were left to agonize about the cause of their seemingly normal daughter's physical and mental deterioration. But then the International Rett Syndrome Foundation was founded and made integrating research, family support and awareness its core mission and funded the research that led to the 1999 identification of the genetic culprit of Rett syndrome. With that breakthrough, and the realization that this rare genetic condition may be the Rosetta Stone of other late-onset neurological disorders from Autism to Schizophrenia, IRSF redoubled its efforts to increase awareness of the disorder. And great progress has been made.

While the Congress and the NIH in the past have initiated some funding for research into Rett syndrome, now is a critical time and we need you to add your voice to the fight for finding a cure to this long-overlooked disorder.

I am sensitive to the demands on your time and appreciate any time you can devote to this meeting. I want to convey to you first hand the exciting opportunities that are presenting themselves to allow us to advance the cause for Rett syndrome by leaps and bounds, not just baby steps.

As little as five years ago, parents typically had a three year wait while doctors went through batteries of tests for less rare syndromes or lived with the imperfect fit of an "atypical" autism diagnosis. Thanks to IRSF's efforts, children are now being diagnosed within months of first seeing a doctor, and tests for Rett syndrome are

becoming part of early screening rather than a test of last resort. It is imperative that we secure government support to continue and expand these successful awareness efforts through the development of a series of conferences, the creation of educational materials, the maintenance of timely dissemination of information via newsletters and the internet and targeting specific audiences of parents, educators, and clinicians. Every diagnosis may lead us closer to solving the mystery of Rett syndrome for my daughter and generations of girls in the future.

I will follow up with your scheduler to try to secure a time for our meeting. In the mean time, if you or your staff would like to reach me, you can do so at \_\_\_[give phone number and email address if possible]\_\_\_\_\_.

I greatly appreciate your consideration of my request and I look forward to meeting with you.

Sincerely,

[name]  
[mailing address and contact info]

Meeting Request Letter (Senate)

[DATE]

The Honorable [Ben Cardin]  
[509 Hart Senate Office Building]  
Washington, DC 20510

Dear [Senator Cardin]:

I am writing to request a meeting with you in your district office in \_\_\_[name location]\_\_\_ during the July Congressional district work period. In particular, I am requesting the meeting with you to discuss a very important and personal matter &ndash; funding for research and activities to increase awareness of Rett syndrome. [If you will be bringing others with you mention that here]. My daughter, [name], has Rett syndrome, a rare and debilitating neurological disorder that was masked in our daughter until she was [age of onset of RTT in your daughter], when she went from a happy, typically developing child to one that is severely disabled, incapable of the smallest acts of independent daily living and unable to tell us her simplest needs.

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