

Letter if You Can't Meet (House)

[DATE]

The Honorable [Pete Sessions]

[1514 Longworth House Office Building]

Washington, DC 20515

Dear [Representative Sessions]:

The House is currently considering the FY 2009 Appropriations bills. In particular, I am writing regarding the House Labor, Health and Human Services and Education (Labor/HHS) Appropriations bill which funds programs that are very important to me and concerns the well-being of my daughter, [Name]. [Name] has Rett syndrome, a rare and debilitating neurological disorder that was masked in our daughter until she was [age of onset of RS 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.

The Labor/HHS Appropriations bill funds many programs that benefit families living with Rett syndrome. But, in particular, this year, Congressman Steny Hoyer has requested \$500,000 specifically for the International Rett Syndrome Foundation to aid in education and awareness for patients, health professionals, and the public regarding Rett syndrome (RTT). Congressman Hoyer's request also includes language that will encourage the NIH to continue its focus on Rett Syndrome research. We urge you to write Chairman Obey and let him know of your support for IRSF and Congressman Hoyer's request.

Until IRSF was founded, no one had heard of Rett syndrome. Parents were left to agonize about the cause of their seemingly normal daughter's physical and mental deterioration. IRSF 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 has redoubled its efforts to increase awareness of the disorder.

IRSF's honorary spokesperson, Ms. Julia Roberts, testified before the House Labor/HHS Appropriations Subcommittee in 2002 to plead for additional research funding. Word of her plea was internationally broadcast, bringing awareness of Rett syndrome from the halls of Congress into living rooms around the world. That year, Congress recommended that NIH create programs targeting research on Rett syndrome. As a result, outstanding breakthroughs have already occurred and the accelerated pace of research is likely to continue with continued Congressional interest in Rett syndrome. We know that by searching for treatments and cures to help [Name], the knowledge gained about Rett syndrome will unlock understanding for more common disorders whose genetic bases have yet to be discovered.

But now is a critical time. By building more awareness and educating the public and health professional about Rett Syndrome, more girls can be diagnosed and more can be learned at this critical moment in RTT research. Congressman

Hoyer has requested the funding from the Public Health Improvement and Leadership account within the Centers for Disease Control, and this is well within that agency's mission.

We know that there are many competing causes bidding for congressional attention. We write to you now to give voice to our girls with Rett syndrome constituency who cannot speak for themselves, but nonetheless add depth, meaning, and indomitable spirit that shapes the foundation of American values and concerns. Thank you in advance for your support of Rett syndrome as you consider the FY09 Appropriations bills.

Sincerely,

[Name]
[Address]

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