

# Meeting Talking Points

(you will have 20-30 minutes, at most)

Opening:

Thank them for their time

Introduce yourself (and your daughter if she's with you; and others if they are with you)

Briefly give them the background on Rett syndrome and your story:

- RTT is a neurological disorder seen almost exclusively in females.
- It is usually caused by a mutation of the MECP2 gene on the X chromosome.
- Early development milestones appear normal, but between 6-18 months of age, there is a regression in skills, particularly affecting speech, hand use and coordination.
- A hallmark of RTT is repetitive hand movements that may become almost constant while awake.
- Other features include seizures, irregular breathing, and curvature of the spine.
- Research can make a difference to provide care today and a cure tomorrow.

Why you are there:

- Until IRSF was founded 20 years ago, no one had heard of Rett syndrome
- The approximately 1 in 10,000 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 redoubled its efforts to increase awareness of the disorder.
- 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.

THE ASK:

We are seeking funding for IRSF 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.

Specifically:

HOUSE:

- Congressman Steny Hoyer has requested \$500,000 from the Public Health Improvement and Leadership account within the Centers for Disease Control for education and awareness for patients, health professionals and the public regarding Rett Syndrome.

- I am here today to ask you to support IRSF and our request by writing to Chairman David Obey and expressing support for Congressman Hoyer's request.

- Chairman Obey is familiar with RTT - Actress Julia Roberts testified before his subcommittee in 2002 on behalf of RTT and funding for research.

SENATE:

- Senator Kennedy has requested \$500,000 from the Public Health Improvement and Leadership account within the Centers for Disease Control for education and awareness for patients, health professionals and the public regarding Rett Syndrome.

- I am here today to ask you to support IRSF and our request by writing to Chairman Harkin and Byrd and expressing support for Senator Kennedy's request.

- Chairman Harkin is familiar with RTT - he has been a friend to Ret syndrome families and our cause in the past.

Get a commitment:

- Get a commitment from the Congressman/Senator or their staff.
- Present your letter asking for their letter to either Chairman Obey, Chairman Harkin or Chairman Byrd.
- Will they write the letter?
- When will you hear back from them?
- Who can you be in touch with when you follow up?

Closing:

Thank them again for their time and for their concern for and support for our girls.

[Back to Top](#)