

IRSF Awarded \$180,000 in CDC grant

IRSF is pleased to announce that we have been awarded \$180,000 from the Center for Disease Control to support education and awareness for patients, health professionals, and the public regarding Rett syndrome (RTT), as well as outreach, registry formation and database build-out to help organize and accurately inform families that are dealing with this debilitating disorder. From this funding, IRSF expects to be able to find and serve more families affected by Rett syndrome, and also support the development of strategic outcome measures to position the Rett community for clinical trials on the horizon.

This grant is the direct result of the advocacy efforts of many families across the nation that have taken time to appeal to Congress for increased federal support of IRSF's Rett syndrome efforts. We thank you for your participation and encourage you to continue to appeal to your Congressmen this year. IRSF is particularly grateful for the leadership and support of Congressman Steny Hoyer (D-MD). Congressman Hoyer has been a long-term supporter of Rett syndrome research and care.

In the next few weeks, you will be asked to support other Rett syndrome advocacy efforts. We are currently updating an online tool to enable communications and grassroots advocacy for the Rett syndrome community.