

## Donna Wright

Donna Wright raised five children in northern Michigan, her home state until she moved to Warren, Pennsylvania with her life partner Bob Dean, an oil and gas industry executive, in 1998, along with her two stepdaughters. She has thirteen wonderful grandchildren, including Naomi, age 7-1/2, who was diagnosed with Rett in 2007. She travels back to Michigan often for extended visits with her family there.

She admits that before Naomi's diagnosis she had never even heard of Rett syndrome, and this has motivated her to do all she can to spread Rett awareness, not only to individuals, but to entire communities, including politicians and medical professionals. In 2009 she became the IRSF's Grandparent Representative for the Mid-Atlantic region. That year she spearheaded successful efforts to obtain gubernatorial Rett Syndrome Awareness Month proclamations from Pennsylvania, West Virginia, Alabama, Alaska and Delaware. After winning the Pepsi Refresh contest in September, 2010, she was again instrumental in assisting and obtaining governor proclamations in 28 states. New Jersey has a permanent Joint Resolution No. 4.

Donna believes that raising awareness is a crucial factor in improving Rett treatment and, soon, she is confident, a cure. She states she feel fortunate to have the opportunity and the energy to devote to that goal. Donna is devoted to spending much of her time in contact with other Rett families across the country, providing information, support, and her message of hope.