

Press Release:
Award-Winning Documentary on Rett
Syndrome Holds D.C. Premiere July 9th
Panel Discussion with Institute of Medicine
President, Leading Rett Scientist,
Filmmaker and Disease Advocate

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Rett Syndrome, a woman's disease most women have never heard of, will be the focus of a documentary film screening and panel discussion. The award-winning film *RETT: THERE IS HOPE*, which showcases the struggles of families living with Rett Syndrome, an autism spectrum disorder that strikes toddler girls, will hold its Washington, D.C. premiere July 9th at 5:30 p.m. at the National Academies' Keck Center, 500 Fifth St. N.W. Members of the public are invited to attend the free screening, reception and panel discussion held with support from the Institute of Medicine (IOM), an independent, nonprofit organization that provides unbiased and authoritative advice to decision makers and the public about the nation's most pressing health and health care questions.

RETT tells the story of three families living with the syndrome and captures the spectrum of emotions ranging from the ever-present stress to the love, devotion, and determination displayed by the affected children, their families, and the scientists working on a cure. Onset of Rett Syndrome is heralded by loss of speech and motor control, including functional hand use. Many children suffer from seizures, anxiety, and severe autonomic, orthopedic, breathing and digestive problems. Most live into adulthood and require total, round-the-clock care.

The panel discussion following the screening will address the impact of rare disease research on the broader community as well as NIH and industry translational efforts. "The long-standing assumption that severe childhood neurological disorders are beyond repair is collapsing, and Rett Syndrome research is a major driver of this new perspective. Families all around the globe who love a child with Rett Syndrome are encouraged and inspired by the current state of research. Our girls are waiting for a cure – time is of the essence," said Coenraads. Panel discussants will feature:

- President of the Institute of Medicine, [Dr. Harvey V. Fineberg](#)
- Institute of Medicine member and RSRT Advisor, Dr. Huda Zoghbi, who identified the genetic cause of Rett Syndrome in 1999 after a 16-year search
- RSRT Executive Director and parent of a teenage daughter with Rett, Monica Coenraads
- President of REM Entertainment, filmmaker [Jason Rem](#)

"It is quite fitting that this film centers on the girls and their families as the scientific community continues to learn tremendously from the patients. Rett Syndrome has played an immense role in my research since the mid 1980's. It's been gratifying to witness and be a part of the growing research momentum. I am optimistic that we will be able to dramatically improve the lives of girls and women who each day battle the effects of this debilitating disorder," shares Zoghbi.

The documentary was made with an all-volunteer effort led by award-winning filmmaker Jason Rem. "Our goal here is to educate D.C. individuals as well as media who can affect change on this debilitating disease. Through the panel discussion, we hope to highlight the issues and brilliant science that is leading to breakthroughs. It is vital that the public at large learns about and appreciates the importance of Rett Syndrome and the science which could lead to a cure," said Rem.

The video has been released for free on YouTube:

[Watch it Now!](#)