

## Black Out Rett Syndrome

GROUNDBREAKING RETT SYNDROME RESEARCH INSPIRES CLINT BLACK PERFORMANCE AT OCT. 27 FUNDRAISER

NEWS FROM: The International Rett Syndrome Foundation (IRSF)

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Country Music Singer-Songwriter Clint Black to Perform at Baton Rouge Fundraiser for October Rett Syndrome Awareness Month

Promising Research Inspires Increased Efforts to help Louisiana Residents and Others; Black's Family Members Come Together to Raise Funding

Baton Rouge, LA – Recent breakthroughs in Rett syndrome research with potential implications for reversing other neurological disorders are inspiring Baton Rouge's second International Rett Syndrome Foundation (IRSF) benefit. Also inspiring these efforts are the more than 200,000 women and children worldwide affected by this condition, and the nearly 100 families affected by Rett in Louisiana. One such Mandeville resident is 33-year-old Lauren Favaloro, who was diagnosed in 1985 at age five at Johns Hopkins by Dr. Andreas Rett, whom the syndrome is named after. Lauren was one of the first 25 children in the United States ever diagnosed with Rett syndrome after her language and mobility skills did not develop normally. As one of the older women in Louisiana affected by Rett syndrome, Lauren's parents Wes and Linda Favaloro still hope treatments on the horizon will benefit their daughter. "We love Lauren as she is, but the thought of her using her hands, gaining the ability to communicate, or progress in daily living skills would be a dream come true," says Lauren's mother, Linda.

"Rett syndrome (RTT) is a genetic neurological disorder that occurs almost exclusively in girls," commented Kathryn Schanen Kissam, Baton Rouge resident and chairman of the board for IRSF. "Rett syndrome becomes apparent after six–18 months of early normal development. It results in a regression that leads to lifelong disabilities including loss of speech, purposeful hand use and mobility. It is often misdiagnosed as autism or cerebral palsy."

On October 27th, 2012, the International Rett Syndrome Foundation and several Louisiana families with daughters who have Rett syndrome are hosting a Southwest Fest, "Black Out Rett Syndrome," at the newly renovated Rural Life Museum in Baton Rouge, LA. The benefit features a live auction and a performance by prolific singer and songwriter Clint Black. Black will be joined on-stage with his brother Brian, nephew Coleton and brother Kevin Black. The Black family will perform to celebrate the memory of Kevin's daughter, Cortney Black, who lost her battle to Rett syndrome. Funds from this event benefit IRSF's Research to Reality Research Fund, chaired by Clint Black. One-hundred percent of net proceeds are earmarked for research. Albemarle Corporation is the presenting sponsor.

According to Kissam, with the discovery of the gene that causes Rett syndrome in 1999 and promising 2007 research that shows the reversibility of RTT symptoms in mice, the pace of innovation in the field of Rett syndrome research and treatment calls for increased efforts. "We now have an unprecedented opportunity to fund crucial new research with the potential to reverse symptoms of Rett syndrome and improve many other related disorders. Because Rett syndrome is a

classic chromatin disorder, it has become the 'rosetta stone' of brain disorders and likely holds the key to unlock treatments and cures for other related disorders including autism, schizophrenia and some forms of mental retardation."

In December 2007, the breakthrough research funded by IRSF which showed the reversibility of Rett syndrome in genetic mouse models was selected as one of the top five most important scientific breakthrough of the year by WIRED magazine. "Increased funding for research could lead to treatments not only for Rett syndrome but for other neurologically based disorders as well," Kissam added. "We are confident that this infusion of resources will help accelerate the translation of basic research discoveries to clinical applications, with tangible benefits for individuals struggling with Rett syndrome."

Somewhere in the world, every few hours a child is born with Rett syndrome. "Rett affects one in 10,000 live female births including my daughter, Reagan," said Dawn Conroy of Lafayette, who is also a host for the event. "I believe the current clinical research which we are trying to fund may one day help change Reagan's quality of life. It will also surely mean that one day another family we will never know won't face the trials of Rett syndrome."

The International Rett Syndrome Foundation is the largest and most comprehensive not-for-profit organization for parents, scientists, interested professionals and others concerned with Rett syndrome. The mission of IRSF is to support and encourage medical research to find a cure and treatments for RTT, to increase public awareness, and to provide information and emotional support to families of children with RTT. IRSF has funded over \$28 million in peer-reviewed research and recently hosted the 7th World Rett Syndrome Congress in New Orleans, LA.

[Click here](#) to purchase a table to the "Black Out Rett Syndrome" event or to support IRSF or call (804) 519-6231. Limited general admission tickets are available for \$100 per individual and include hors d'oeuvres, cocktails and a southwest dinner.