



# Silent Angel

By Sue Mayfield Geiger

Cortney Black was sixteen when she died in March 2003, but she is very much alive in the hearts of her family and friends.

Born a normal, healthy infant, symptoms of Rett Syndrome (RS) did not appear until Cortney was fifteen months old, characteristic for the disorder. Parents Kevin and Patricia Black knew very little about this rarity that affects one in 10,000 to 15,000 births; primarily females. Because they eventually lose all forms of communication, they have become known as "silent angels" to the RS community.

Rett Syndrome is a debilitating neurological disorder that usually occurs six to eighteen months of age, causing loss of speech and motor skills. Most develop repetitive hand movements, irregular breathing, seizures, gait abnormalities and mental retardation. RS leaves its victims profoundly disabled, requiring maximum assistance with every aspect of daily living. There is no known cure.

Before symptoms begin, remarkably the child appears to grow and develop quite normal. Loss of muscle tone is usually the first symptom. Problems crawling or walking may occur, plus diminished eye contact. Autistic-like behavior in the early stages are common. Although the majority of females live into adulthood, Cortney lost her battle at age sixteen.

Kevin Black, along with brothers Brian, Mark and Clint (yes, that Clint Black), was raised in Katy, Texas. His humble upbringing and

wide grin are the kinds of things typical of songwriters, so it was only natural that he became one. "Music was my life from the time I could hold a guitar," says Kevin. He sang anytime, anywhere, any place. He eventually found himself on stage at clubs, honky-tonks and people's living rooms – even construction sites. As with most artists, they have to have a day gig. Kevin's was hanging steel.

It is a custom in the building industry to install a Christmas tree to the apex of a steel building on the day it is completed. When the owner of the construction company where Kevin worked decided to visit the jobsite on a day when a building had been finished, he was surprised to see, not a Christmas tree atop the building, but a temporary bandstand complete with drums, amps, base, and guitar, along with Kevin and his fellow musical workers. They were five stories up in the air, entertaining the plant workers and passing traffic by belting out song after song.

Meanwhile, brother Clint's career was reaching mega proportions. Kevin was proud of Clint and continued on his own path. But all the while, the sadness of Cortney's debilitating illness was hard on the Black family. Since statistics show that most girls with RS live into adulthood, Cortney's untimely death was a shock. Although, it has been three years, Kevin still grieves mightily for his daughter, and is doing everything he can to bring awareness to a disorder that is misunderstood by many.



*The Black family: Dad, G.A.; Brothers Mark, Brian, Kevin, Clint.*

"In smaller communities, RS is often misdiagnosed," says Kevin. "The symptoms are not recognized, so the victims and their families suffer even more. Our main focus is to bring attention to RS through public awareness and fundraising events."

So, mark you calendars, folks. The Tee it Up for Rett Syndrome Celebrity Golf Tournament is September 26. Meander on down to Humble, Texas and play golf with Kevin and Clint Black, their brothers,

family, friends, and a gaggle of celebrities coming to town to bring attention to Rett Syndrome. Redstone Golf Club is the place, located at 5860 Wilson Road (home of the Shell Houston Open). If you are a Clint Black fan and feel like hanging out with Kevin and all the Black brothers, this is your chance. Besides golf, there will be a silent auction and good eats. Celebrities attending (other than those good looking Black brothers) are: Daryl Gardner (for-



*Kevin Black testifies in front of the House Appropriations Labor, Health and Human Services, and Education Subcommittee.*

mer) Miami Dolphins, Washington Redskins player; Gary P. Nunn, singer/songwriter; Larry Dierker, (former) Astros player/manager; Dan Pastorini, (former) Houston Oiler quarterback; John Granato, Sports Radio talk show host; Gene Peterson Houston Rockets announcer; Doug Pike, sports writer; Roger Creager, Texas singer/songwriter; and many, many more entertainers and sports icons.

But, celebrity fundraising is just a minor part of Kevin's crusade. In March of this year, he testified in front of the House Appropriations Labor, Health and Human Services, and Education Subcommittee advocating for increased federal funding of RS research and related disorders. He has also been involved in numerous efforts and fundraisers to raise the awareness of Rett Syndrome.

Then on May 30, over 300 parents, children, leading researchers and clinicians gathered in San Francisco for the 22nd International Rett Syndrome Association Annual Conference. The conference entitled, "Bridges to Hope," is the world's largest and most comprehensive gathering of stakeholders seeking to find cures and treatments associated with this rare neurological disorder that impacts girls. Highlights of this year's conference included presentations by leading researchers and clinicians on topics, which featured various therapies, nutritional issues, communications assistance and orthopedics. In conjunction with this event, IRSA's President and Founder Kathy Hunter awarded Kevin with The President's Award for Outstanding Advocacy. The President's Award for Outstanding Advocacy is presented annually to public servants and children's advocates who have sacrificed personal gain for the betterment of girls with RS. The International Rett Syndrome Association board of directors created this particularly poignant award to honor those who give voice to the

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Kevin and one of the "Silent Angels" affected by Rett Syndrome.

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issues and needs of children with RS, something the girls themselves are deprived of doing because of the impact of this devastating disorder. Previous recipients include Congressman Steny Hoyer (D-MD) and the actress Julia Roberts.

In accepting this honor, Kevin said, "I am proud to receive this award to honor my daughter, Cortney. As a parent who has lost a precious child to RS, I can think of nothing more important than investing in research to build upon the amazing progress we've made toward finding a cure." Kevin continued, "It's too late for Cortney. But for thousands of other kids who live with Rett Syndrome, we need to keep searching for answers. The only way we get there is through research and public awareness. I believe some day we will have a cure. Until then, I will do whatever I can to persuade public officials and private donors to dedicate investment dollars to solving this medical puzzle."

To say that Kevin is on a mission is an understatement. He is bound and determined to bring attention to this disorder that does not seem to get enough press. Basically, RS was originally discovered by Dr. Andreas Rett of Austria in 1954. He published his findings in 1966 in several German medical journals, but it wasn't until the early '80s that RS came into the mainstream when an article describing the syndrome was published in a well-known scientific journal. "We suspect there are thousands of girls and women undiagnosed or misdiagnosed (eg. autism, cerebral palsy)," says Kevin. Although rare, it is possible for boys to have RS.

Ironically, the gene responsible for causing Rett Syndrome was discovered right here in Houston by research fellow Ruthie Amir. The medical team was led by Dr. Huda Y. Zoghbi, professor of pediatrics and human and molecular genetics at Baylor College of Medicine in 1999.

The Black family is a close-knit bunch. They have come together for this cause and will continue to do so. Clint Black issued this statement: "My entire family and especially my brother, Kevin has suffered so much pain over the loss of Cortney, Kevin's only daughter. At age 16, she was taken by the dreadful disorder Rett Syndrome. This golf tournament in which I'm participating is dedicated to my niece, Cortney with the benefits going to the Rett Syndrome Association. Our efforts are projected with the hope that we can be a small part of donating to the research for a cure of RS and spare other families this grief. My brothers, Mark, Kevin, Brian and my Dad G.A. will all band together on that day, hoping that the Black family can make a difference."

So, come and spend time with Kevin and Clint and all the others. Enjoy lunch, a great round of golf at Redstone, dinner, auction, and awards ceremony. Oh yes, and all the committed celebrities. (Admit it. You know you want to get some autographs and hang with these guys. Who wouldn't?) For more info, visit [www.cortneyblackfund.org](http://www.cortneyblackfund.org) or [www.rettsyndrome.org](http://www.rettsyndrome.org) or call 713.410.6076. Also, be sure and visit [www.kevinblack.com](http://www.kevinblack.com). (Editor Note: Special thanks to Dave Clements for photos.)