



Bob Riley
GOVERNOR

Alabama Department of
REHABILITATION SERVICES



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FOR IMMEDIATE RELEASE

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Governor names Feb. 28 'Rare Disease Day'

BIRMINGHAM— When 15-year-old Kelsi Moore was born with Costello syndrome, the Birmingham resident was only the 18th person in the world diagnosed with the disorder.

Although there are now between 250 to 300 people in the world with Costello syndrome, the condition is still considered rare because it affects fewer than 200,000 Americans. Because so few people have Costello, few Americans are aware that it even exists.

To increase public awareness of this and other uncommon diseases, Gov. Bob Riley recently signed a proclamation designating Feb. 28 as “Rare Disease Day” in Alabama. This will also be the first time the nation will recognize the last day of February as “Rare Disease Day.”

The National Organization for Rare Disorders (NORD) organized the day in the United States to call attention to the public health issues associated with rare diseases, which affect nearly 30 million Americans and countless others around the world. This will be the second time for the worldwide recognition.

“People with rare diseases remain a medically underserved population in every country,” said Peter Saltonstall, president of NORD, which is sponsoring Rare Disease Day in the U.S. “This day is intended to bring together the patients and families with rare diseases to discuss the need for greater awareness, more research, and better access to diagnosis and treatment.”

Tammy Moore, Kelsi Moore’s mother, initiated the effort to get the governor to sign the proclamation through her role as the president of the Costello Syndrome Family Network (www.costellokids.com). She said she is grateful the governor agreed to sign the proclamation.

“Most people simply don’t know about some of the more-uncommon diseases,” Moore said. “This day means so much to me because it gives me, as a parent, the opportunity to educate the public about my daughter’s disease.”

Costello syndrome is a rare genetic disorder that causes short stature, characteristic facial features, loose skin, feeding difficulties and heart problems.

Kelsi and other Alabamians with rare diseases can receive assistance through the Alabama Department of Rehabilitation Services (ADRS), the state agency whose mission is to enable Alabama’s children and adults with disabilities to achieve their maximum potential. Through its four major programs, the department provides medical, educational and employment assistance to people of all ages.

For more information about ADRS, call 1-800-441-7607.