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## Local mom raises awareness for daughter's rare syndrome

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Marie DeWoody pushes and steers a modified bike down the hall at Pediatric Physical Therapy Services in Lafayette while a physical therapist oversees her every move. Her mother, Yssa DeWoody, stands close by watching, waiting and encouraging her to keep going.

"This gets her hips moving and simulates gait," said Yssa of Lafayette. "It loosens her up and gets her a little bit more willing to walk."

Yssa knows the value of every step. Although Marie is 7 years old, she has severe developmental delays because of Ring 14 syndrome, a rare genetic mutation of the 14th chromosome. One of the major symptoms Marie has to endure is drug-resistant epilepsy. Since infancy, she has experienced a cluster of seizures — six to 18 — every 10 to 14 days. Recently, she's gone five weeks without a seizure. During that break she has started to take her first steps without needing to hold a caregiver's hand.

But Yssa worries that another seizure will wipe out her daughter's progress.

"She'll have a cluster of seizures and we'll have to start all over again," she said.

The impending worry doesn't stop Yssa from cheering her daughter on. Yssa co-founded Ring 14 USA Outreach with a California mom last fall. The nonprofit organization aims to promote and fund research initiatives to discover treatments and therapies for children with this type of disorder, to raise awareness of Ring 14 syndrome and to provide community for the families that are affected.

Although the organization is based in California, the board of directors — dedicated mothers of children with the

Written by TAYA FLORES

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**What:** Ring 14 USA Outreach will hold an Italian dinner as its first local fundraiser

**When:** May 14; the fundraiser's auctions, hors d'oeuvres and live music will begin at 6 p.m., followed by dinner and a program at 7 p.m.

**Where:** The Outpost, 2501 Old 231 South

**Cost:** Admission is \$50 per person, or \$150 for a family of up to five people. Those interested can become a Friend of Ring 14 and sponsor a table of eight for \$500. To register, email Yssa DeWoody immediately at [yssa@ring14usa.org](mailto:yssa@ring14usa.org).

For more information about registration, auction items or the menu, visit the website [ring14usa.org/register/charity-dinner](http://ring14usa.org/register/charity-dinner).

disorder — come from all over the country.

"The fact that it's so rare, there is very little community," Yssa said. But the mothers involved were able to find each other via the Internet.

A rare syndrome, Ring 14 is caused by a genetic mutation of the 14th chromosome. The 14th chromosome breaks in two places and the broken ends fuse together, forming a ring or circular chromosome. People with

Ring 14 have one copy of this abnormal chromosome in some or all of their cells, according to National Institutes of Health.

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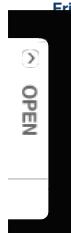
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