

## 2<sup>nd</sup> Annual Walk-a-Thon for CDKL5 Research

*All proceeds benefit CDKL5 Research*



### Event Schedule Saturday, August 7, 2010

**8:00am**  
Registration

**9:00am**  
Walk begins

**10:00am**  
Raffle – *great prizes!*  
Live Music  
Family Fun  
Light Refreshments

#### Where:

Richmond High School track  
35320 Division  
Richmond, MI 48062  
*(directions on back)*



[www.cdkl5.com](http://www.cdkl5.com)

#### Directions to Richmond High School:

##### From Detroit:

Take I-94 East toward Port Huron

Take exit 247 for MI-19 toward Richmond/New Haven

Turn left at MI-19/New Haven Rd (signs for Richmond/New Haven)

Turn right at Gratiot Ave/MI-19 and drive approximately 6 miles to Main Street

Turn left at S Main St/MI-19, proceed for another 1.4 miles then

Turn left at Division Rd

After turning left on Division, proceed to the Middle School drive, turn left and park in Middle School Parking lot. The Middle School lot is just behind the high school track.

#### For More Information:

##### Call:

Janet Baker at 248-245-0614, or Katheryn Elibri Frame at 734-426-7789

##### Email:

[info@cdkl5.com](mailto:info@cdkl5.com) or [KatherynEF@yahoo.com](mailto:KatherynEF@yahoo.com)

**To learn more about CDKL5 or to donate online,** visit [www.cdkl5.com](http://www.cdkl5.com)

ALL PROCEEDS BENEFITING

International  
Foundation For

**CDKL5**  
RESEARCH



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**Saturday, August 7, 2010**

8:00am – 12:00pm  
Richmond High School track  
Richmond, MI

Supported by the Richmond Lions Club



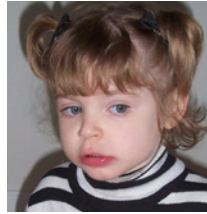
# What is CDKL5?

**CDKL5 is a rare X-linked genetic disorder** characterized by early onset, difficult to treat seizures, and severe neuro-developmental impairment. There are fewer than 200 documented cases in the world, but as awareness of CDKL5 disorders spreads more children are being tested, and the number of children affected by CDKL5 continues to grow weekly.

CDKL5 affects mostly girls, but there are boys with this disorder, too. There is a broad constellation of symptoms, and the child may have been diagnosed as having Infantile Spasms, West syndrome, Lennox-Gastaut, Rett Syndrome, Early-onset intractable epilepsy, or Autism. Most of these children suffer from seizures that begin in the first few weeks of life. Most cannot walk, talk or feed themselves. Many are confined to a wheelchair and are dependent on others for everything. The majority of children also have scoliosis, visual impairment, sensory issues and severe gastrointestinal difficulties, some of whom require feeding tubes.

In 2009, the International Foundation for CDKL5 Research (IFCR) was formed by a group of parents whose children have CDKL5. IFCR is a 501(c)(3) non-profit, whose mission is to fund global research efforts in search for a cure; to raise awareness of CDKL5 disorders; and to support families affected by CDKL5 by providing information, education, and resources. For more information, please visit [www.cdkl5.com](http://www.cdkl5.com).

## Bella's Story



Our beautiful 5 ½ year old **Izabella Lucille** was diagnosed with CDKL5 over 2 years ago. The future that was once imagined and expected is now uncertain but hopeful. With triumphant effort, we make it

our daily goal to allow our daughter to live a happy and independent life!

Bella loves school, where she learns social and practical life skills. She gallantly endures extensive hours each week of physical and speech therapies. For added fun and socialization she enjoys swimming, horseback riding, playing ball, and walks in the cool breezes.

Bella is a sweetheart who has brought great joy to our lives. Our child has taught us so many things we never expected, and has inspired us to raise awareness and find a cure for this devastating disorder. CDKL5 has changed the future we envisioned for Izabella and the futures of over 200 children worldwide. Finding this cure will mean more than saving our child, it will change the lives of hundreds of children and families like ours. Thank you for helping us reach our destination.

## Kiera's Story



**Kiera Grace** took her first independent steps when she was 3 years old, and it was a miracle! We had been told that Kiera would never walk, talk, or have any kind of normal life, but our daughter continues to

prove the doctors wrong. She is now 4 years old, and can pedal a tricycle and is learning to talk!

Kiera was born perfect head to toe! When she was just two months old, out of nowhere, she had her

first seizure. Her life – our lives – were changed forever. She continued to have severe seizures daily, and became very delayed in her development. It took three long years, and many tests, to find the answer: a mutation on the CDKL5 gene.

Through it all, Kiera is a truly joyous, happy little angel – her smile and laughter are contagious! Kiera is sweet, funny and curious. She is extremely hard-working, tolerating many hours of weekly therapy.

We tell Kiera everyday “We wish love were enough,” but our abundance of love is only the beginning of what Kiera needs. So love is where we start. Thank you for your prayers and support.

## Kimmie's Story



**Kimberly Grace** was born in March 2005. Her first seizure occurred when she

was only 2 months old. Our world was about to be turned upside down. She endured many tests before we finally got

the heart shattering diagnosis of CDKL5. Kimmie is severely multiply impaired. She cannot speak, crawl, or walk and she relies on us for everything. Everyday we struggle to gain control of her seizures.

Despite all these challenges, Kimmie is famous! She has three older sisters, a huge family and even more friends to spoil her. Our little girl is very vocal, and she thinks its funny when we tease her for telling elaborate “stories.” Kimmie is very sure that she is the boss of all of us and we wouldn't have it any other way. She loves attention, heavy metal music, being told how gorgeous she is, and the wind in her hair. Kimmie is a very happy little girl and her smile can heal you. She is everything to her family.