

# STAND UP & BREATHE

KARLY WAHLIN'S STORY



Karly Wahlin is a smiley young woman with Rett Syndrome. Often diagnosed at infancy, girls who have Rett Syndrome tend to experience hyperventilation and breath holding. When people with Rett's hold their breath, it often causes them to feel faint and dizzy. "From when Karly wakes up in the morning, to when she goes to bed at night, she is holding her breath and hyperventilating," Karly's mom, Lois says. "The only time Karly is not holding her breath is when she is in her EasyStand stander, or with her miniature horse," Lois continues. Karly's mom is unsure exactly why these activities calm Karly so much, and for Lois, the outcome is more important than answering why.

Name: Karly Wahlin

Primary Diagnosis: Rett Syndrome

Date of Onset: Birth

Date of Birth: July 4, 1985

Residence: Stillwater, Minnesota

Height: 5'7"

Stander Used: EasyStand Evolv



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## TALLER THAN AVERAGE

Karly is 5'7", which is very tall for a girl with Rett's. Often Rett's girls are shorter in stature. Lois remarks, "It makes Karly nervous when she has to depend on other people to support her, especially when the other people are often smaller than her. So, when she uses her stander in school, she feels very calm and supported." She goes on, "Her teachers and therapists notice a significant change in her breathing when she stands. Using her EasyStand makes Karly feel independent, because she isn't counting on the support of other people to help her stand. She is fully supported by the EasyStand because it has the right kind of supports to make her feel secure."

## SETTING GOALS FOR GRADUATION

Sometimes when Karly is standing at school, she will listen to music on her headset or hangout with friends. This makes her feel more independent because she enjoys being the same height as everyone else (and sometimes taller!). Lois remarks, "It is important to Karly to be more at eye level." Karly is currently using the stander at her transitional school; she does not have a stander at home. Since Karly is graduating in 2007, Lois' goal is to get Karly an EasyStand to use at home by the time she graduates. After seeing the benefits Karly experiences while standing at school, she knows that Karly's standing program needs to continue at home.

## KARLY'S FRIEND BEAU

Beau is Karly's miniature horse. When Karly took therapeutic riding lessons, her family discovered that she didn't hyperventilate when she was around the horses or on the back of a horse. So in August of 2005, Karly's family got a miniature horse for her. Standing about 35" tall, Beau is allowed in the house on occasion, but is mostly outside with Karly on the deck, in the garage or in the back yard. Beau is an important part of Karly's overall health and a friend to Karly.

## COMMUNICATING WITHOUT WORDS OR SIGNS

Even though Karly cannot communicate verbally, she uses a ground breaking new communication device to express herself. The communication device is a Cyberlink Headband which detects electrical signals from Karly's brainwaves which trigger the mouse and keyboard, allowing Karly to talk without her mouth or hands. With the use of this communication device, Karly was able to tell us about standing from her point of view. Karly said, "I love to stand by myself in the stander. When I do that I am more independent. It is relaxing to stand. It gives my back a break from sitting in my chair at school all day. I like it because I am not nervous when I stand in it like I am when someone supports me."

**CHALLENGE:** REGULATE KARLY'S BREATHING AS MUCH AS POSSIBLE.

**SOLUTION:** PRACTICE A REGULAR STANDING PROGRAM AND PARTICIPATE IN A THERAPEUTIC RIDING PROGRAM.

**CHALLENGE:** CONTINUE TO RECEIVE THE BENEFITS OF STANDING AFTER GRADUATION.

**SOLUTION:** GET A STANDER FOR HOME USE TO CONTINUE AN ONGOING STANDING PROGRAM.

**MEDICAL BENEFITS:**  
REGULATE BREATHING  
STRETCH BACK

**PSYCHOLOGICAL BENEFITS:**  
RELAXING  
FEELING MORE INDEPENDENT  
LOOKING OTHERS IN THE EYE

