

## Sonja's Journey with myGaze

Sonja, the girl with Rett Syndrome, is able to make choices, communicate her needs and operate simple PC applications, all within a 3-month trial with myGaze Assistive eye tracking device.

By Sara Barbee, mother of an awesome Rett girl Sonja



Sonja Barbee has Rett Syndrome and lost all her verbal and hand skills by the age of 2. Sonja is going to turn 17 soon. She lives in West Linn with her family and goes to Wilsonville High School. Sonja loves music and dancing and also much enjoys when her family or friends read books to her.

*“What we know about Rett Syndrome is that there is so much in their heads, and you can tell it, but very rarely are they able to express it.*

*With myGaze device, we see our daughter make choices that she has never had the ability to make. We see the potential for true communication.”*

*---- Sara Barbee*

### THE BACKGROUND

#### Sonja, A Girl with Rett

Sonja Barbee has Rett Syndrome and lost all her verbal and hand skills by the age of 2. Unlike many other girls with Rett, though, Sonja is generally healthy.

Garth, Sonja's father, is a doctor and I (Sonja's mother) work as a physical therapist. We have been searching for a while for a suitable system to help Sonja communicate with us.

### THE CHALLENGE

#### Enabling Basic Communication

We have tried low tech ideas and high tech ideas with Sonja to help her communicate – very little true success. Rett Syndrome's real challenge is motor planning. Sonja has no verbal or hand skills and is often challenged with how to communicate basic wants and needs with someone who does not know her well.

## THE SOLUTION



### myGaze is More Than Just Another Eye Gaze Experiment

Eye gaze technology is amazing, but most devices have been designed for people who once had but lost their ability to communicate (ALS, quadriplegia etc). The eye gaze system simply replaces their lost ability to speak or type. For someone like Sonja, however, who never had a chance to build those skills it was important that the system was intuitive and made sense to her, or otherwise she would never make the effort.

Our interest in myGaze came from experiencing the failure of other options. The failures are many: 1) incredibly expensive, 2) rigid with a very small window to read Sonja's eyes, 3) poorly designed software making it ridiculously difficult to program or modify. There is still much to learn from myGaze, but it is reasonably priced, it is much more forgiving to Sonja's head movements, and it appears to be easier to set-up and use in a variety of ways.



Video: An Interview with Sonja's Mother - Journey with myGaze

## THE RESULT

### Make Choices, Communicate and Control the PC

The operation of myGaze has been done mostly by Sonja's school Speech Pathologist and partially by ourselves at home. We have found, the system is easier to operate, easier to modify, and easier to use with software that we can program.

Sonja is currently using it daily in school and her aids see Sonja answering questions and making choices with myGaze. The ability to have people understanding you is a very powerful thing. We specially love that it can be used for making choices online (Facebook, Youtube, emails). As Sonja's therapist said, Sonja is really progressing so well with the device. (See progress chart)

### Progress in First 3 Months

Quotes from Lucas Steuber, Sonja's Speech Pathologist.

*"The dwell time and calibration ease have been fantastic for her to get started."*

*"It was very engaging for her, allowed for a great deal of accuracy and limited distractions."*

● 2/30/2015

● 4/3/2015

● 5/5/2015

● 5/20/2015

watch the video

Video: Sonja's first trial of myGaze device

*"Sonja was very emotional when she discovered her ability to select YouTube videos with her eyes!"*

*"Sonja is, indeed, very good at the Eye Mouse games, and she is having a lot of fun."*