



# Our Friend, Keilly

Concept and delivery created by Amy Nessel, MA School Counselor  
Roger Ludlowe Middle School 2011

# What is Rett's Syndrome?

- **A unique neurological disorder – meaning that Keilly's brain has challenges to work like your brain.**
  - 1) More specifically, there are problems in the parts of the brain that are responsible for thinking and moving.
- **Rett Syndrome has wide range of disability from mild to severe.**

# Rett Syndrome as it relates to Keilly

● **Keilly does not have the ability to speak.**

- 1) She talks with her eyes.
- 2) The direction of her gaze tells you what she wants.
- 3) The sparkle in her eye gives you a sense of how she is feeling.



# Rett Syndrome as it relates to Keilly

● Keilly has some physical challenges

1. It's hard for her to use her hands.
2. It's very common for kids with Rett Syndrome to rub their hands together a lot.
3. Keilly has trouble using a fork or spoon but is really good at eating finger foods on her own.

# Rett Syndrome as it relates to Keilly

## ● It's hard for Keilly to walk.

- 1) Keilly is a good walker and is steadier than she looks. Her legs just don't move as easily as yours do.
- 2) Getting up out of a chair or walking up stairs is hard for her.

# How Keilly Communicates?

- **Keilly has a response button that she uses.**

- 1) It has greetings, questions, and information about what she might like to talk about.

- **Keilly has an iPad2.**

- 1) She uses it to communicate and learn.

- **Keilly also uses her eyes to communicate.**



# How is Keilly JUST like you?

- 1) She loves music!
- 2) She has favorite foods, watermelon especially!
- 3) Her friends mean so much to her and she LOVES spending time with them!
- 4) She loves to swim!
- 5) She has feelings and moods- she feels happy, sad, frustrated and tired, just like all of us do!

# How is Keilly JUST like you?

7.) She likes to read and to be read to.

8.) Because of the bright colors, art is one of her favorite classes.

9.) Keilly loves Chorus class and listening to the songs while Mrs. Lafond plays the piano.

10.) Daydreaming- looking out the window at all the activity is fun.



# Being a good friend to Keilly!

## ● Talk to her just the way you would talk to others

- 1) You just have to be patient. Keilly has a processing delay- meaning it takes her brain longer to decide what to do or how to respond.
- 2) Just wait a little bit longer. She will appreciate that you understand!

# Being a good friend to Keilly!

● **She can hear you just fine.**

- 1) There is no need to speak more loudly.
- 2) Just use a regular tone of voice.

# Being a good friend to Keilly!

## ● Having good eye contact helps Keilly when you are talking to her.

- 1) Just like you and me, it's always nicest when the people you are talking to are looking you in the eye.
- 2) There are so many reasons why good eye contact is important. For Keilly, it really helps her to feel connected to you and to see your facial expression while you are talking.



# Making new friends- What I have learned from Keilly's best friends!

## **Keilly loves...**

Books, music, movies, butterflies, sitting in bean bag chairs, eating Pirate's Booty, computer games, art projects and so much more.

# Interested in being a good friend?

- ❖ Consider joining Keilly during HR to read a book with her during SSR time.
- ❖ Come join Keilly at her lunch table. There is always room to pull up another seat.
- ❖ Share that you are interested in joining Keilly's Friendship Group with your teacher or Mrs. Nessel.
- ❖ Offer to read a book that can be video recorded for Keilly to enjoy after school or over the weekend.

# Learning and Fun and RLMS...

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# Project Adventure classes!



# Keilly in Art Class ...Celebrating a special day!





# Friends enjoying Keilly's Butterfly Garden



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# Keilly enjoying the End of the Year Trip



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## 7<sup>th</sup> Grade on Crew S...

Keilly is ready for all of the adventures that lie ahead. Everything is better when shared with a friend.