

Maastricht, March 31st 2017



Dear parents and therapists,

Over the last 5 years the number of individuals with Rett syndrome that have access to proper Augmentative and Alternative Communication has increased. Many individuals are now using Eye Gaze technology to operate a Speech Generating Device in combination with other low-tech options. For example, ABC flip books, choice making symbol charts.

More and more stories and examples of clever, funny and spot-on messages are being shared through Facebook and other social media platforms. It's encouraging and inspiring to read about how individuals communicate in day-to-day situations. These examples are accessible to other parents and some professionals. We believe that more people should see and read about the brilliant things individuals with Rett syndrome have communicated by using AAC.

To accomplish this, we want to start collecting photographs and written reports of real life examples of communication of individuals with Rett and the people around them. We are hoping to use those pictures and descriptions for future presentations (for example: the next European Rett Conference in Berlin) and would love to make a magazine celebrating communication in Rett syndrome.

Share your story

If you are willing to share some of your stories, please send them to us by e-mail with the subject 'Rett story' and a short description containing the following information:

- First name of the individual
- Age of the individual
- Country
- Situation
- Message communicated by the individual
- Screenshot(s) or photographs of the message and/or communicative setting

Example

Email subject:	Rett story
First name:	Anna
Age:	15
Country:	Netherlands
Situation:	Anna was sitting in the living room as her brother started playing the piano.
Message:	Anna smiled and started giving complements using her eye gaze device. "You, I Like, music, listen" "good, you, sing!"
Photograph/ screenshot:	Add to the e-mail as an attachment

Please feel free to send in examples in any language.

Be aware that by sending your examples you give permission for us to use them for future presentations and publications to celebrate communication.

Kind regards,

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