


ÖRSG
 Österreichische Rett-Syndrom Gesellschaft


rse
 General Assembly
 Vienna, November 15

Ready or not?

Our Rett-Girls find their „Voice“
in Eye-Gaze Technology




Romana Malzer
 Isabellas Mum
 AAC-Consultant




LIFEtool[®]
computer aided communication


1960er • Rett-Syndrome was discovered
by Dr. Prof. Andreas Rett




1998 • localization of the gene
mutation



2014 • but on question remains:
How much do they understand?




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The „silent girls“ are talking with their eyes.



We parents know:
Our girls use their Eyes to welcome friends, to show us something, to want something, or to ignore somebody or something.

Could it be possible, that some of these girls spend their lives in isolation, in an imaired body but with a clear mind?

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Evidence of knowledge?

- „Show me ...“
- „Do you know ...“
- „Can you ...“

Apraxia ☹️

Once more:

We parents know, that our kids understand us!

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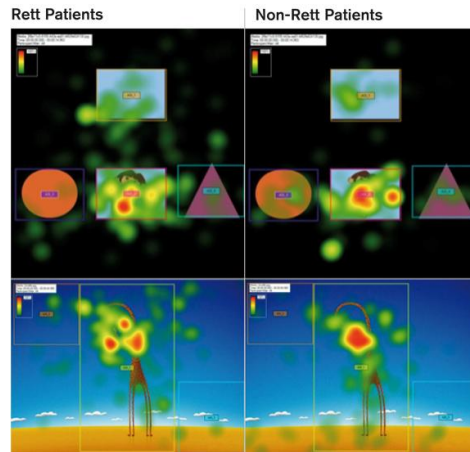


Studie Rett-Syndrom Center in Montefiore, NY 2012 (Djukic, A. et al)

Question:
"Can Rett Syndrome patients differentiate between the more important and less important aspects of an image by giving more attention to the relevant (focal) stimuli?"

31 Rett-girls attendet

The control-group were parents, hospital-personnel.



[http://www.pedneur.com/article/S0887-8994\(12\)00019-7/abstract](http://www.pedneur.com/article/S0887-8994(12)00019-7/abstract)

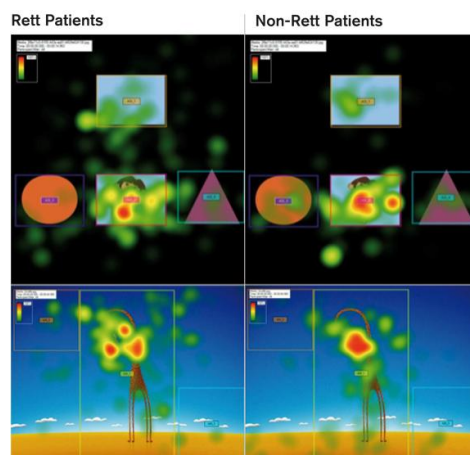
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Studie Rett-Syndrom Center in Montefiore, NY 2012 (Djukic, A. et al)

Rett-Syndrompatienten appeared to demonstrate **similar fixation patterns** compared to non-Rett-patients!!

NO significant Differences!



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Dr. Aleksandra Djukic:

Eye gaze technology allowed us to give Rett Syndrome patients a voice – a way to communicate their perception of what they see.

This is of immeasurable value because most of these patients have no other way to communicate their knowledge.”



Dr. Aleksandra Djukic

Rett Syndrome Center, Children's Hospital at Montefiore, Albert Einstein College of Medicine
www.montekids.org/services/leadership/neurology/rett-syndrome



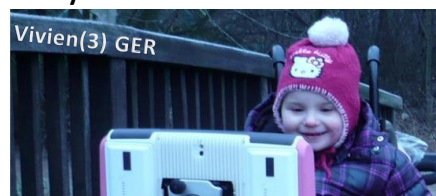
<http://www.medicalnewstoday.com/releases/205709.php>

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„She is **not ready** to use eye gaze?“

- Why?
 - She is able to walk?
 - She doesn't need EyeGaze – she uses switches?!
 - she shows no interest in using switches
 - she shows no interest on communication
 - ev. miss-interpretation?
- even NO chance to try! ☹️



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EyeGaze Technology



- two cameras built in
- Infrared-light shine a nearly imperceptible light on the eyes
- the camera "sees" the reflection of the light off the pupils
- an algorithm turns the information from the camera into "mouse" movement
- the user looks at a point on the screen and that is where the cursor goes or
- the user looks at a square on screen for approx. 0,5 sec a click will be activated
- a synthetic voice speaks



Tobii-Geräte mit Augensteuerung

NEW!



I-series

C-series



PCEyeGo for laptop



BUT the real core of these devices
No High-Tec Computer...



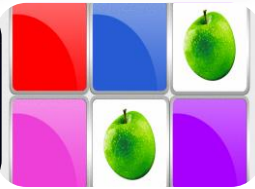
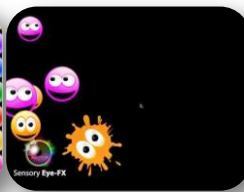
... but container for Language & Quality of Life



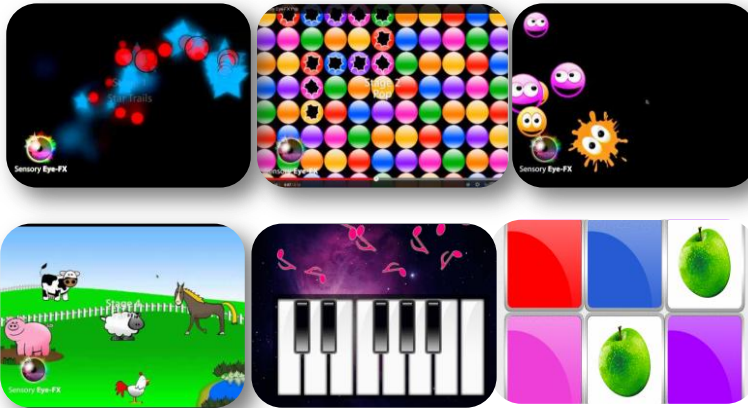
Communication = cause&effect



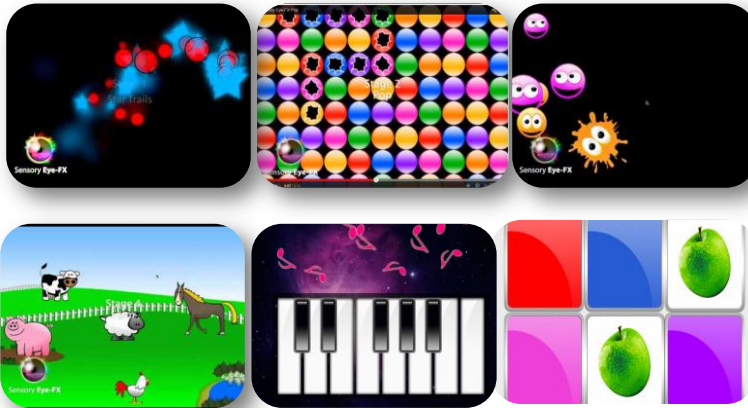
Sensory EyeFX



Communication = cause&effect



Communication = cause&effect



Communication = Connection

Use the device to PLAY games & make music!



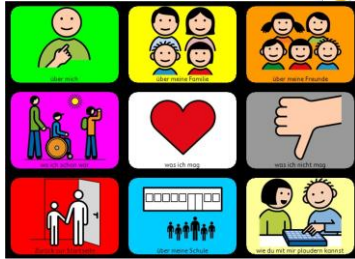
Communication = Connection

Use the device to PLAY (p.e. voice-activated toy (dog) – activated by device



Communication = Connection

Use the device to show pictures and tell stories about me, and any theme

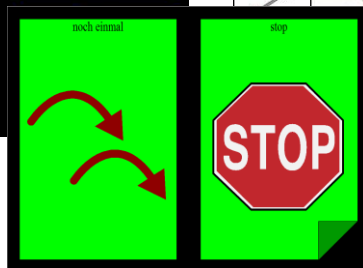
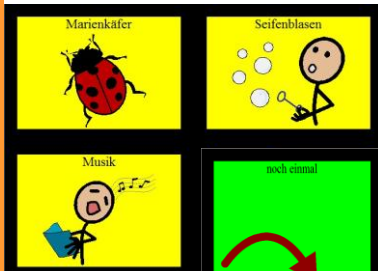


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Communication = Choices

Use the device to make choices

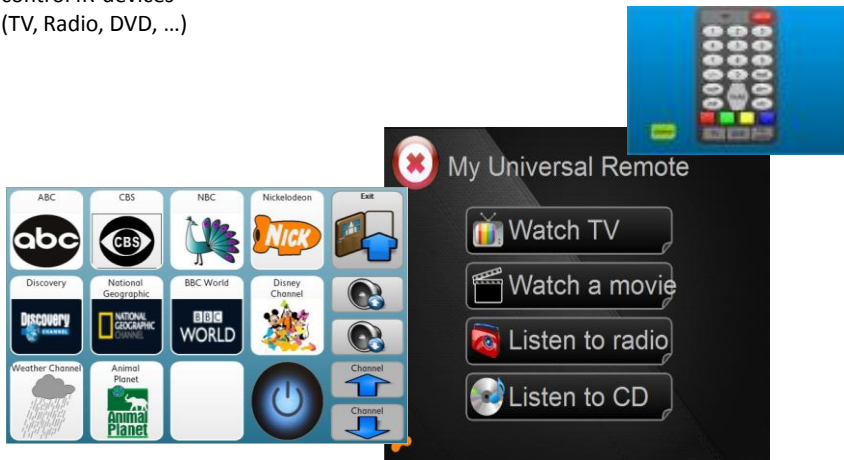


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Communication = Control

Use the device to control IR-devices (TV, Radio, DVD, ...)



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Communication = knowledge

Use the device to use Eye accessible Learning Software



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Parents voices:

- **“The Tobii C12 has life with our daughter not made any easier.** Now, we have to put up with comments like ‘stupid’, ‘yucky’ and ‘boring’.

But we are learning more and more about our daughter's personality and we are better able to deal with her wishes.

She is more satisfied, more agreeable and she can play on her own, listen to music or watch a short video – overall she lives a more independent and richer life.”

(Stephi Bo, DE)



Parents voices:

- “We never heard from AAC till Alexa got 28 years – it is never too late to start with UK! And 5 y later we heard of the EyeGazeTechnology, but we thought, it would be too difficult for her, but it isn’t! – She got the tobii when she was 36 y — Alexa loves to communicate!”

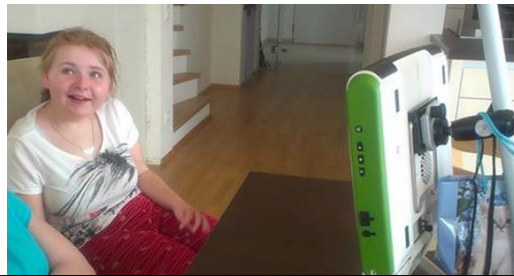
Fam. Pickenhan, DE



Parents voices:

- “For Vanessa (15) – it is a new kind of life-quality – she can tell her experiences and choose her own music or ask questions – never dreamed, that she could do this one day in this way ...”

Family Peckary, AT



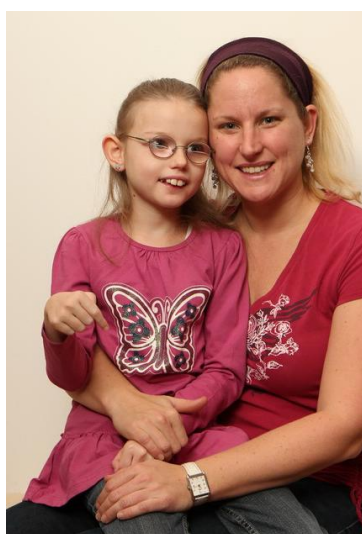
*quick - quick - cool - thanks -
i want to talk to you - yes - thanks
- i want to talk to you - thanks -
thanks - yes - thanks - my talker -
thanks - cool!*



German Literature (Rett & AAC)



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“They feel all the love given to them. They have a great sensitivity for love. I am sure of this.

There are many mysteries, and one of them is the girls' eyes.

I tell all the parents to look at their eyes. ***The eyes are talking to them.***

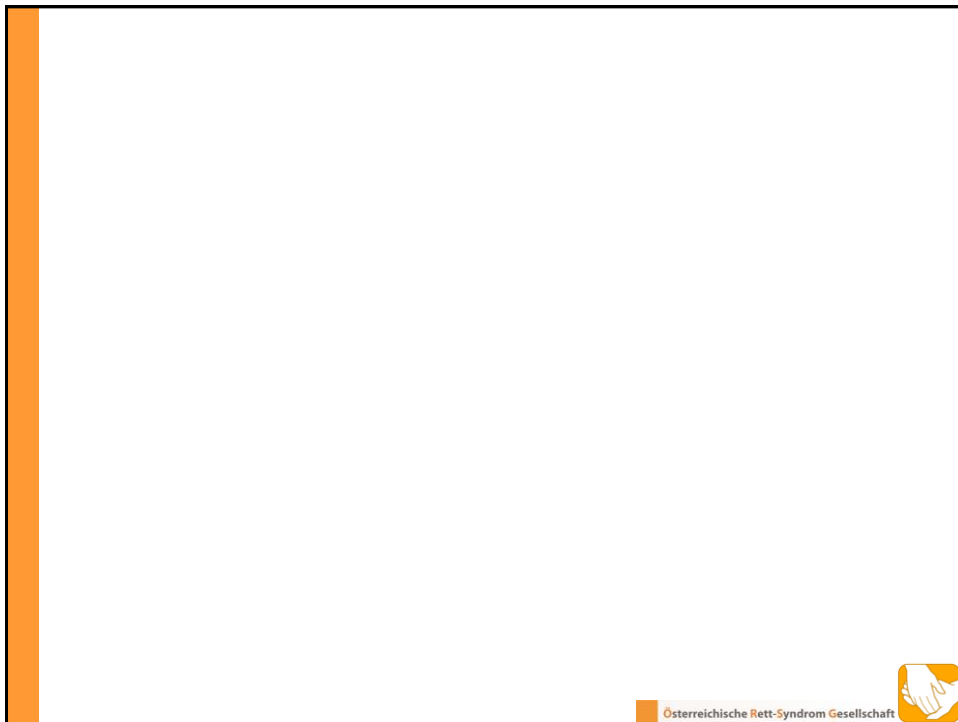
I am sure the girls understand everything!

Prof. A. Rett

<http://www.rettsyndrome.org/understanding-rett-syndrome/about-rett-syndrome/history?>

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No-tech Methods

- symbols/pics/objects without voice output
- facial and body language
- Eye gaze
- Communication Boards



Aut. Öst. Volkshochschule



Low tech Methods

- Switches for Cause-Effect
- Step-by-Step

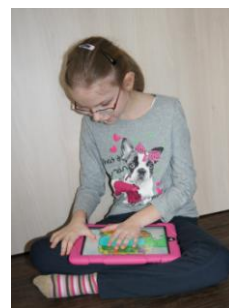


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iPad for Rett-Kids?

- **Cause & Effect Apps** (touch or switch)
 - TouchMe-Apps
- **Playing Apps**
 - GoTalkNow



<http://www.janefarrall.com/switch-accessible-apps-for-ipadiphone-non-aac/>

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SwitchAccess for iPad

- List of switch-accessible Apps:

- <http://www.janefarrall.com/switch-accessible-apps-for-ipadiphone-non-aac/>



- usefull hardware:

- Applicator (Pretorian)
 - NewBlue2











- Usefull covers

- Griffin survivor
 - BigGrips
 - BestCool for iPad



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EyeGaze is an Option – not THE answer!

 <p>Songs on the BigMack</p>	 <p>Switch-adopted toys</p>	 <p>Switch-Games on PC</p>	 <p>Reading with BigMack/SbS</p>
 <p>Choose of foto-cards</p>	 <p>Choosing of symbols</p>	 <p>Integrate symbols in everyday life</p>	 <p>Daily routine with fotos and symbols</p>

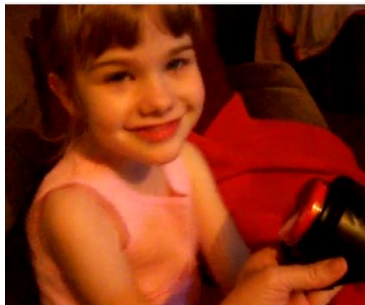
 <p>made books with pics and symbols „My summer,“ ...</p>	 <p>Claim activity with Step-by-Step</p>	 <p>Daily calendar with symbol-messages for school->home</p>	 <p>We adopted anything – really anything!!</p>
 <p>Social scripts on the Step-by-step</p>	 <p>Touch-device with 3x3 keyguards (2007)</p>	 <p>HeadTracker (2010) with Laptop and tobii communicator</p>	 <p>Tobii C12 with Cdot (2011)</p>

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„Hit the button with whatever works ...“

- The girls find individual and creative ways to use the switches without using their hands!



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Rett and AAC - Problems

- daily changing forms
- peripheral vision and react additionally
- stereotypes
- inhibited when high expectations apperent
- unexpected flash alternatives
- Problem, to repeat an action directly

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Rett and AAC and Apraxia

- Ask others to wait while she builds a message
- “Wait, count and pray!”
(Carolin Musselwithe)
- “Everything is possible,
but don’t expect it!”
(Chris Hirsch)
- Please believe in the Girls!
They notice, if they are
taken seriously, or not!



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Helpful Things



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