



**Rett Syndrome Center**  
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August 3, 2010

Re: Childs Name  
DOB: 1/6/2005  
From: Aleksandra Djukic, MD, PhD

To Whom It May Concern:

\_\_\_\_\_ is a five year old girl with Rett Syndrome. Rett Syndrome is the only pervasive developmental disorder with a known genetic cause. It is a neurodevelopmental disorder and one of the most common causes of severe impairment in females. The peculiar clinical abnormalities of Rett Syndrome arise from a mutation in a gene for Methyl-CpG binding protein 2 (MECP2), which is located on Xq28.

Severe apraxia is the core feature of Rett Syndrome. Apraxia is the basis for a child's inability to speak, and to use her hands. Since she cannot use her hands, she has been unable to use devices such as Tango, Intellikeys or any other device that requires direct access through hand use.

Rett patients are known to have specific preference oriented towards people and have genuine interest in establishing communication. Due to their medical condition, they are unable to communicate verbally. However, their nonverbal communication is effective and purposeful. Speech Generating Devices (SPG) such as PRC and Tobii C12 are specifically designed for nonverbal individuals and are a medical necessity.

With an appropriate device, a child quickly learns to use a device to express her own voice. This is the necessity that allows these children to develop to the best of their cognitive and medical ability.

Timing of introduction is essential. It has been well known for more than thirty years that the impact of appropriate stimulation has different effects at different stages of life. These periods are known as the "window of opportunity" and the "window of vulnerability."

This child is within the window of opportunity where appropriate engagement has a direct impact on the development of brain structures. Therefore, as a neurologist and the director of the most comprehensive Rett Center in the United States, I consider this to be a medical necessity which unfortunately cannot be replaced by any prescription drugs.

Fortunately she effectively communicated via her eye gaze and was able to easily calibrate an eye gaze device. Analysis of her tracking (enclosed pictures) clearly demonstrated that Anna not only can point with her eye gaze but that her searching strategies are meaningful and also ability to be sufficiently focused in order to memorize presented stimuli.

All these facts are very encouraging in terms of her ability to mobilize her neuronal networks when appropriately engaged. Activation of neuronal networks is an essential prerequisite for development and strengthening of synaptic connections. Lack of appropriate engagement even if children of \_\_\_\_\_'s age who are not impaired can have detrimental effect on development of brain functions. Therefore and from neurological standpoint this equipment is considered to be not a basic human need but also a medical necessity for \_\_\_\_\_. It is also her legal right to be able to communicate.

Though Rett Syndrome is a devastating disease, the scientific community considers it curable in the future.

I recommend that \_\_\_\_\_ receive the following:  
Prentke Romich Company (PRC) the ECO-2

Please do not hesitate to call me if I can be of any further assistance.

Sincerely,

Aleksandra Djukic, MD, PhD  
Associate Professor of Neurology and Pediatrics  
Director, Rett Syndrome Center