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Diplomate and Senior Disability Analyst, American Board of Disability Analysts

[REDACTED]

[REDACTED]

Re: [REDACTED]  
Docket No: [REDACTED]

Dear Judge [REDACTED],

Pursuant to my appointment as guardian ad litem in this matter, I have today completed a review of medical records regarding the above named child; these include records of [REDACTED] and [REDACTED], including records of Drs. [REDACTED], [REDACTED] and [REDACTED]. In addition, I also conferred with Dr. [REDACTED], the pediatric neurologist at [REDACTED] who first diagnosed [REDACTED] with Rett Syndrome, Dr. [REDACTED], pediatric gastroenterologist at [REDACTED] who has been treating [REDACTED], Dr. [REDACTED] (by e-mail), pediatric neurologist at [REDACTED] and specialist in Rett Syndrome who examined her in consultation, Dr. [REDACTED], pediatric gastroenterologist and member of the [REDACTED] Rett team who examined her in consultation and Dr. [REDACTED], medical director of the Child Protection Team at [REDACTED]. Additionally, I contacted the attorneys in the case and asked whether there were any specific questions regarding the medical care that they wished me to address in my investigation and report.

Rett syndrome is a neurodevelopmental disorder that affects girls almost exclusively . . . caused by a mutation in the [a] gene. . . . Most cases are spontaneous, which means the mutation occurs randomly. . . . There is no cure for Rett syndrome. Treatment for the disorder is symptomatic — focusing on the management of symptoms — and supportive, requiring a multidisciplinary approach.<sup>1</sup>

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<sup>1</sup> National Institute of Neurological Disorders and Stroke / NIH, Rett Syndrome Fact Sheet, 12/18/09, available at [http://www.ninds.nih.gov/disorders/rett/detail\\_rett.htm](http://www.ninds.nih.gov/disorders/rett/detail_rett.htm).

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There are multiple associated medical conditions including scoliosis, cardiac anomalies, cholecystitis and breathing irregularities.<sup>2</sup> Children with Rett Syndrome require monitoring by appropriate specialists to deal with these associated medical conditions, but these specialists do not need to be experts in Rett Syndrome.<sup>3</sup> Based on the records reviewed and the conferences with treating and consulting physicians, this reviewer would conclude that [REDACTED]'s past care to date has been medically reasonable and appropriate.

After consulting with the attorneys in this case, I was asked to address three questions which I did with each of the physicians with whom I conferred. The questions are as follows.

1. Is there a relationship between [REDACTED] having Rett Syndrome and the ongoing acute medical problems that she has had in the past year?
2. What is the likelihood that the colonoscopy in February was the cause of the intra-abdominal bleed in March and April?
3. Is it possible that the acalculous cholecystitis was the underlying cause of intra-abdominal bleed?

There was no conflict in the responses of any of the physicians conferred with, either treating or consulting, from [REDACTED] or [REDACTED].

1. The consensus of all physicians who rendered an opinion was that it was unlikely in the extreme that there was a relationship between [REDACTED]'s having Rett Syndrome and the ongoing acute medical problems that she has had in the past year.
2. The consensus of all physicians who rendered an opinion was that it was unlikely in the extreme, if not impossible for the colonoscopy in February to be the cause of the intra-abdominal bleed in March and April. Dr. [REDACTED] stated that there were no complications from that colonoscopy, and that it was longer than usual because he performed both a colonoscopy and an upper bowel endoscopy. In order for the colonoscopy to have caused the bleeding, the bowel would have had to have been perforated and at no time was there ever any indication of a perforated bowel, which is usually a life threatening emergency.

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<sup>2</sup> *Id.*

<sup>3</sup> Personal communications with treating and consulting physicians.

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3. The consensus of all physicians who rendered an opinion was that it was unlikely in the extreme for the acalculous cholecystitis to be the underlying cause of intra-abdominal bleed.

The recommendation of this reviewer, confirmed by a unanimous consensus of the physicians with whom he conferred, both in [REDACTED] and [REDACTED] is that it would be in [REDACTED]'s best medical interest to continue her treatment at [REDACTED]. Consultations with the Rett team at [REDACTED] should be made routinely on an annual basis unless the treating physicians believe that other consultation is indicated.

Respectfully submitted

Mordechai Kamel