

Case History Report Form

Child details (* required)

Name (first name only) or *Code	Vanessa
*Chronological age (CA) Actual age since birth	6 years
*Diagnosis and/or presenting problems	Aicardi Syndrome (see below) Epilepsy Severe developmental delay
*Other products used List other products used by the child as part of their 24-hour postural management programme. State where and how the products are used.	

Therapist details (* required)

Name or * Code	
Address	Italy
Contact number	
Email	
*Profession / qualification	PT
*Number of years qualified	
*Number of years experience with children	

Product details (* required)

*Product name	Mygo Seating System on Otto Bock Skippy Power Base
*Components or accessories used	Pelvic support system

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Assessment details . complete before using the product

Date 07/ 03 /2008

Child's weight
Height / length in supine Delete as appropriate
<p>Developmental history, assessment, clinical observations, functional abilities Include a description of the problem/need/weakness the child has. Append copies of assessment report / outcome sheets where appropriate.</p> <p>Vanessa has Aicardi syndrome - a rare genetic disorder identified by the French Neurologist, Dr. Jean Aicardi in 1965. The number of identified cases of children with Aicardi syndrome is very difficult to calculate accurately, but has been estimated at 300 - 500 worldwide.</p> <p>Aicardi syndrome is characterized by the following "markers":</p> <ol style="list-style-type: none"> 1. Absence of the corpus callosum, either partial or complete (the corpus callosum is the part of the brain which sits between the right and left sides of the brain and allows the right side to communicate with the left.) 2. Infantile spasms (a form of seizures) 3. Lesions or "lacunae" of the retina of the eye that are very specific to this disorder 4. Other types of defects of the brain such as microcephaly, (small brain); enlarged ventricles; or porencephalic cysts (a gap in the brain where there should be healthy brain tissue). <p>Aicardi syndrome only affects females. Children are most commonly identified with Aicardi Syndrome before the age of five months. A significant number of these girls are products of normal births and seem to be developing normally until around the age of three months, when they begin to have infantile spasms. Treatment of Aicardi syndrome primarily involves management of seizures and early/continuing intervention programs for developmental delays. For more information, see http://www.aicardisyndrome.org/.</p> <p>Vanessa was born at term with no complications, and the pregnancy was normal. At two and a half months, she developed seizure episodes with increasing frequency. Vanessa was re-admitted to paediatric care, where the following test results were obtained: EEG showed slow frequency oscillations; MRI showed agenesis of the corpus callosum (ACC), and frontal bilateral micropolygyria. A treatment cycle of ACTH was started, along with vigabatrin therapy (anticonvulsant drug). Subsequently, various drugs prescribed for epilepsy were tried (vpa, tpm, Zonegram, Rivotril): the decision to use Keppra and LTG was made in February 2006.</p> <p>Vanessa is a lively child. She smiles at the sight of someone's face. She vocalizes. She can fix her attention upon objects and pay attention for short periods of time. Attention span is severely reduced. She is poor at mimicry, and lacks ability to modulate her voice. Independent mobility is limited, and lacking direction. Vanessa also suffers orthostatic hypotension to a moderate-to-serious degree. Reflex protective support action by the upper limbs is absent; she has partial control of her head, which does not roll. The L.S.S. (Level Seating Scale) puts her at a scale of 2 (in need of support from the trunk down to the hips). In the sitting position, supported at the hips, she has a tendency to fall to the right side; of its own accord, the head tends to flex downwards/sideways, but in response to stimulus or if reminded, Vanessa can maintain her head vertically for more than 30 seconds at a time. Vanessa does not try grasping motions, nor reaching. Grasping or holding behaviour, when it occurs, is prevalently on contact, but it is not efficient, nor is it directed towards exploratory behaviour.</p>

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Treatment strategy/goals for child

These should be very specific and measurable

The rehabilitation technician arrived on the 7th March 2008 for %T₀ + and measured the GAS objectives, marking down the relative scores (see table). Furthermore, the family objectives were defined, to be checked at the next follow up (T₁).

Using modified Goal Attainment Scaling (GAS), the T₀ therapy goals for Vanessa are:

Therapy Goals T ₀	Worse than expected -1	Achievement of the defined objective 0	Better than expected +1
Posture Alignment	An inclination of the trunk to the right side persists	The trunk and the head are symmetrical. The pelvis is vertical, the thighs held parallel. Able to maintain stability of the head for more than 30 secs without any support X	Able to maintain stability of the head for at least 1 minute without support
Interaction with peers and family	Only occasional eye contact	Able to maintain eye contact with an adult for at least 15 seconds X	Able to maintain eye contact for more than 15 seconds
The child's well being	Less than 2 hours	Able to maintain the seated posture without crying or complaining for at least 2 hours per day X	More than 2 hours
Meal time	Continues to be fed while in mother's arms	Makes use of the adaptive seating device for at least one meal a day N.D.	Makes used of the adaptive seating device for more than one meal a day
Visual function	Able to fix on an object temporarily	Able to fix on an object and follow the object over an arc of 45° through the air in front of their eyes X	Able to fix on an object and follow the object over an arc greater than 45° through the air in front of their eyes
Handling Objects	Casual contact of the arm with the object in question	Intentional contact of the arm with the object X	Intentional contact with the object by means of the hand.

The score N.D. (no data) was assigned for the %meal time+objective because on this first occasion for evaluation (T₀), it was not possible to test for the desired result; for all the other objectives, it was possible to assign a score of %0+.

Description of your planned intervention

State what your expected outcomes for the child are from using the product. List components to be used and why?

Vanessa used a Peg Perego pushchair and a Foppa Perdetti high chair, neither of which afforded any kind of postural support in the sitting position. The use of the Mygo with a base for indoor use was suggested, together with later use of a base for outdoor use (Kimba 2).

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Review Assessment 9th May 2008

Record review results. Repeat initial assessment stages as appropriate, noting any improvements / deteriorations / new problems encountered / solutions. Note any changes to the configuration of the Leckey product, i.e. components added / removed. If possible, re-photograph your child.

Return to Clare Wright (Clinical Research Manager) at clare@leckey.com or by post after each review.

Review of therapy goals at 3 months (T₁):

Therapy goals T ₁	Worse than expected -1	Achievement of the defined objective 0	Better than expected +1
Posture Alignment	An inclination of the trunk to the right side persists	The trunk and the head are symmetrical . The pelvis is vertical, the thighs held parallel. Able to maintain stability of the head for more than 30 secs without any support X	Able to maintain stability of the head for at least 1 minute without support
Interaction with peers and family	Only occasional eye contact	Able to maintain eye contact with an adult for at least 15 seconds X	Able to maintain eye contact for more than 15 seconds
The child's well being	Less than 2 hours	Able to maintain the seated posture without crying or complaining for at least 2 hours per day	More than 2 hours X
Meal time	Continues to be fed while in mother's arms	Makes use of the adaptive seating device for at least one meal a day	Makes use of the adaptive seating device for more than one meal a day X
Visual function	Able to fix on an object temporarily	Able to fix on an object and follow the object over an arc of 45° through the air in front of their eyes	Able to fix on an object and follow the object over an arc greater than 45° through the air in front of their eyes X
Handling Objects	Casual contact of the arm with the object in question	Intentional contact of the arm with the object	Intentional contact with the object by means of the hand. X

The family's review of objectives at 3 months (T₁) after the introduction of the Mygo posture system were as follows:

T1 Family	Worse than expected -1	Achievement of the defined objective 0	Better than expected +1
Lessening the physical stress of the primary care giver	More than 5 X	Avoiding repeated repositioning/adjustments over the course of the day (less than 5 times)	No need to stabilize / No need to re-adjust repeatedly
Interaction with peers and family	Only occasional eye contact	Able to maintain eye contact with an adult for at least 15 seconds X	Able to maintain eye contact for more than 15 seconds
The child's well being	Less than 2 hours	Able to maintain the seated posture without crying or complaining for at least 2 hours per day	More than 2 hours X
Meal time	Continues to be fed while in mother's arms	Makes use of the adaptive seating device for at least one meal a day	Makes use of the adaptive seating device for more than one meal a day X
Handling Objects	Casual contact of the arm with the object in question	Intentional contact of the arm with the object	Intentional contact with the object by means of the hand. X

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The scores recorded by the T₁ rehabilitation technician confirmed the score of 0+ (objective attained) for the first two objectives (posture alignment and interaction with peers and family) but there was improvement for the last four, with a score of +1 (better than expected).

The scores recorded by the family at time T₁ confirmed the score of 0+ (objective attained) for the second objective, revealed a score of +1 for the last three and a score of . 1 (worse than expected) for the first objective. The negative score can be explained by the necessity on the part of the parents to re-stabilize Vanessa's head several times during the course of the day. Her mother furthermore suggested that the attachment system for the tray could be made simpler, by means of quick-release clips that would avoid the need to screw/unscrew the knobs.

