

PREEMIE GROWTH PROJECT
PHASE 2: INFANTS & CHILDREN WITH NEUROMUSCULAR ISSUES
June 2012 – July 2013

PARENT REPORT SAMPLE EXCERPTS

This is one of eight documents containing samples of parent reports from the “Phase 2: Infants and Children with Neuromuscular Issues” feasibility study that was run from June 2012 through July 2013. Specific analysis and conclusions can be found at <http://www.preemiegrowthproject.com/for-your-doctor/results-of-feasibility-study/> and specific breakdowns by neuromuscular diagnosis and gestational age are available at the website.

It should be noted not every subject saw improvement in every category, but overall, 111 children out of 134 (83%) experienced improvement in four or more defined categories.

It should also be noted not all parents reported the initial status of their children in each category and some did not recognize their child had a particular issue until after improvement was seen. This was especially true for “Sensory Processing” – only 20 children were reported as having this diagnosis yet 43 children were seen to improve.

Specific categories that were tracked were: Tone & Strength, Weight & Height, Cognition, Communication, Bowel Function, Appetite, Energy and Sensory Processing.

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II. Changes in Weight & Height (830 Reports): 116 of 134 (86.6%) Improved

Participant 002 - Male (5 Yrs, 7 Mon):

Day 67 - Gained three pounds, and two/three inches.

Participant 058 - Male (2 Yrs, 1 Mon):

Day 70 - He is ALWAYS hungry. I also know he is taller because I have had to adjust his stander height twice in the last month.

Participant 154 - Male (4 Yrs, 5 Mon):

Day 105 - Grew an inch, gained a pound

Participant 090 - Male (1 Yr, 1 Mon):

Day 122 - Woo hoo!! We gained another pound!!! Yay! His appetite has increased and he's eating great!

Participant 045 - Female (3 Yrs, 6 Mon):

Day 24 - Gained a pound after 10 days on supplement. First weight gain achieved in over 6 months.

Participant 105 - Female (7 Yrs, 4 Mon):

Day 36 - She has grown 7/8" in one month without gaining any weight!!!

Participant 102 - Female (6 Yrs, 8 Mon):

Day 72 – [Child]’s appetite has typically been fairly consistent. In the last week, she began taking a new medication for ADD, which has decreased her appetite. Her weight has increased by 2lbs since beginning the PDCM though.

Participant 111 - Female (3 Yrs, 9 Mon):

Day 130 - Weight up 1/2 lb since last weigh in.