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# Clinical course of growth in patients with congenital neuromuscular disease in a single multidisciplinary neuromuscular clinic.

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### Abstract

**OBJECTIVE:** To assess the effect of nutritional interventions on growth and on respiratory status in patients with congenital myopathy (CM), congenital muscular dystrophy (CMD), and congenital myasthenic syndrome (CMS).

**METHODS:** Retrospective cohort study based on case-note review of 18 patients affected by CM, CMD, and CMS, followed at a single pediatric neuromuscular center, between 2006 and 2014.

**RESULTS:** Seventy-two percent of patients required placement of a gastrostomy tube for bulbar weakness or for growth failure. Of those patients, 10 had 1 year follow up anthropometric data and 6 had 2 year follow up anthropometric data. Height percentiles and z-scores were significantly improved in patients after 1 year, while weight and BMI percentiles and z-scores were not. Weight and height percentiles and z-scores were significantly improved in patients at 2 year follow up, while BMI percentiles and z-scores were not. The number of respiratory illnesses was not significantly different before or after placement of the feeding tube. Of the patients who did not have placement of a gastrostomy tube, 4 had 1 year follow up anthropometric data and 3 had 2 year follow up anthropometric data. Gastrostomy tube fed patients had significantly higher mean weight percentiles and z-scores compared to orally fed patients. There was no significant difference in height or BMI between the gastrostomy fed and orally fed groups. Individual growth curves highlight the effect of intervention on weight and height.

**CONCLUSIONS:** This is a single multidisciplinary center experience describing the effect of nutritional interventions on growth in patients with congenital neuromuscular disorders. While the number of patients and their data in this report are limited, it highlights that the growth in this group of patients is unique but that the low weight and short stature respond to nutritional interventions with changes typically seen after 2 years of intervention.

**KEYWORDS:** Congenital myopathy; congenital muscular dystrophy; congenital myasthenic syndrome; gastrostomy tube; growth; nutrition; respiratory status

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