

Non-Ambulatory Patient Experiences Better Outcome with New Generation Portable Pump

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A developmentally delayed child diagnosed with Mitochondrial Electron Transport Chain-Complex III deficiency MET(C-III) by 1-year of age. MET(C-III)-deficiencies are rare, manifested in heterogeneous clinical presentation: cytochrome b, optic atrophy, cardiomyopathy, encephalomyopathy and a reduction in maximal oxygen consumption

General History and Nutritional Evaluation

At age 5 years, 10 months, a Gastrostomy tube was placed due to a gradual decline in ability to consume liquids and solid food resulting in poor growth, constipation and dehydration. Patient was unable to talk, sit, or walk and was below 5th percentile for height and weight on growth chart. In addition, a neurological manifestation developed; a juvenile Parkinson overlap syndrome that included random movements at rest and during physical exertion requiring physical therapy to improve strength and regain muscle control.

Bolus feedings administered for 2-months. Feeding goals were rarely achieved due to daily emesis causing missed feedings. Patient changed to gravity feedings for 4-months resulting in minor improvement in daily emesis. However, patient was sensitive to rate fluctuations and tubing would frequently occlude when roller clamp was adjusted to reduce rate.

A new generation portable pump (NGPP) was initiated at 6 years, 4 months for 30 - days. Feeding tolerance was immediately improved by a consistent delivery rate. A trend toward goal rate and dose requirements was achieved.

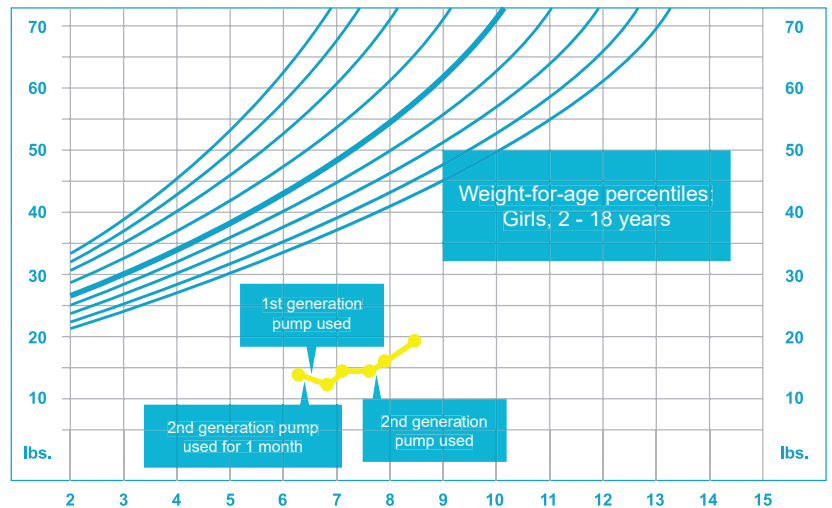
Reimbursement for the NGPP was denied by insurance carrier and patient was converted to a first generation portable pump (FGPP). Improved tolerance to enteral nutrition continued, yet patient experienced emesis for week long periods of time. Caregiver believed inaccuracy of pump was tied to the episodes of emesis. Pump dose delivery rate repeatedly exceeded rate setting. Frequent rate adjustments, occlusions of feeding bag set, and unreliable pump battery charging

became troublesome for caregiver and school nurse resulting in two costly pump exchanges by home infusion provider.

Patient was again converted to the NGPP at 7 years, 5 months per pediatric gastroenterologists' recommendation, based on reliability and specified accuracy (+/-5%) from pump manufacturer*. Within 3 weeks, patient was able to achieve goal rate and dose consistently. Patient's emesis resolved, weight gain occurred and strength increased supported by physical therapy documentation. By 8 years, 2 months old, patient achieved ability to stand and take steps with a walker.

Outcome

Although patient remains confined to a wheelchair, significant clinical benefits and quality of life improvements have been achieved by receiving enteral nutrition via a NGPP.



- At 5-months of pump use, patient had surpassed 5th percentile on weight-per-length growth chart and no longer experiences emesis due to feeding intolerance.
- Small backpack pump carrier has reduced stigma associated with feeding SbbScSfge that is different from other children.
- Psychosocial benefits include dramatic improvement in class room participation. There is no longer need to be removed from activity for an alarming pump or frequent slow gravity feedings.
- Caregiver reports no problem to date with NGPP and cites additional benefit of easy pump cleaning by washing it under running water.
- Improvements in strength continue.
- Patient continues to thrive.

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