

## **Guidelines for Gastrostomy Tube Feeding for Infants with Neuromuscular Disease**

**Formula Options:** At this time, there is no good data on whether a specific brand or brands of regular infant formulas are better tolerated in infants with SMA type I or other more severe forms of neuromuscular disease. Even after infants get a gastrostomy tube (g-tube), they can continue to benefit from receiving breast milk, which contains valuable proteins to help bolster an immature immune system. If the infant still has the ability to safely feed orally as documented by a swallow study (but perhaps received a gastrostomy tube due to poor weight gain or a single aspiration event during illness), he or she can sometimes still be breast or bottle fed, but supplemented additionally as needed with breast milk or formula via g-tube. In this case, weekly monitoring of weight gain can help guide appropriate g-tube supplementation. Obviously, infants who choke or sputter with feeds are at risk of aspiration, and feeding should be restricted to g-tube only.

Elemental formulas are easier to digest because they contain free amino acids rather than whole proteins; however, they don't taste good, are much more expensive, and are not clearly superior to regular formulas for those infants who tolerate them. Elemental formulas with lower fat content may be better tolerated than those with higher fat content, such as Neocate. Many babies have abnormal gastric emptying, and a lower fat, elemental based formula such as Vivonex may be more ideal for those babies demonstrating reflux or other difficulties tolerating feeds. Since babies with neuromuscular disease have a lower lean body mass, lower metabolic rate and thus lower calorie requirement, the quantity of formula should be adjusted as needed to meet the baby's growth requirements, with a goal of maintaining weight for length ratio of 10-25% (See Neuromuscular General Nutrition Guidelines). Constipation is frequent in infants with neuromuscular disease, and can add to abdominal bloating and discomfort and worsen reflux. Regulation of bowel movements with glycopyrrolate or a promotility agent such as metoclopramide may be indicated if they aren't having at least one or more bowel movements every day.

**Feeding Strategies:** Children with SMA type I and other neuromuscular disorders may have some difficulties tolerating bolus feeding, so that smaller more frequent bolus feeds during the day may be best, every 3 hours or so, especially if they don't have a Nissan. All babies spit up (have reflux), but with SMA babies this is much more frequently a problem, particularly if their ability to protect their airway is compromised. Proactive respiratory care using a cough assist machine or BiPAP can allow some air into the tummy, which can further aggravate the situation. Be sure to vent the g-tube during treatments with the cough assist, and when on BiPAP. Keep the baby's head and body up at least at a 30 degree angle from horizontal for at least 30-60 minutes following a bolus feed. A wedge under his/her mattress or play area works well, or a seat that is angled so that the tummy isn't compressed. Don't assume he or she won't tolerate regular formula until you try it, as some babies tolerate regular formula without difficulty. If he or she fails to tolerate the regular formula with bolus feeds, a continuous feeding regimen using a pump may be helpful, or smaller bolus feeds during the day in combination with continuous nighttime feeds. Finally, if those strategies fail, we recommend substituting an elemental formula which is lower in fat, such as pediatric Vivonex.

Last updated 1/2010 by Kathryn Swoboda, M.D. , University of Utah. These recommendations are guidelines only; please consult with your physician regarding specific care concerns in you or your child. For questions regarding this document, you may email [swoboda@genetics.utah.edu](mailto:swoboda@genetics.utah.edu).