

Coenzyme Q10 (CoQ10) & Prader-Willi Syndrome

PWSA (USA) Clinical Advisory Board, revised Feb. 2006, March/April, "The Gathered View"

Coenzyme Q10 (or CoQ10) is a naturally occurring vitamin-like substance in the body. CoQ10 is essential in energy production in all living cells, especially in the muscle. If deficient in CoQ10, an individual may feel less energetic, have reduced muscle function and have a decreased metabolic rate. CoQ10 also acts as an antioxidant in the blood and all cell membranes.

Individuals with PWS may have decreased levels of CoQ10. A blood test can determine if an individual's CoQ10 level in the blood is lower than normal. A muscle biopsy would be the best way to determine cellular CoQ10 level, but at this point we do not feel muscle biopsies are warranted.

When CoQ10 levels are low, supplementing with CoQ10 may help increase energy level, muscle function and metabolism. Some parents also see an increase in activity and attentiveness after supplementing the child with PWS with CoQ10. However, while some parents feel that their child demonstrates improvements with CoQ10, others feel that it has no effect. Also, parents should be clear that CoQ10 supplementation is not a substitute for growth hormone treatment which has clearly been shown to have multiple benefits for individuals with PWS.

The information we have on the effectiveness of CoQ10 is all "anecdotal" data (i.e., from parents commenting on their personal experiences with their child). There have not been any controlled scientific research studies about the effects of CoQ10 in individuals with PWS. At this time, there are no KNOWN adverse side effects of taking CoQ10 if taken in an appropriate dose.

The recommended starting supplemental dose of CoQ10 varies according to different groups. It is anywhere from 1-30 mg. per kg per day for infants, and no more than 180-200 mg per day for older children. We have typically found that 60-100 mg per day in the older children and adults is sufficient to raise the blood level to the normal range in those individuals who were initially found to have low levels. If families are contemplating supplementation with CoQ10, we would recommend testing a blood level before and after starting CoQ10. Dissolved CoQ10 in softgel capsules (which contain vitamin E and other lipids to help the body absorb the CoQ10) are better absorbed than dry powder CoQ10 tablets or capsules. The CoQ10 softgels typically come in 60- or 100-mg doses. Therefore, older children and adults will need to take 1-3 capsules per day.

CoQ10 can be purchased over-the-counter at most pharmacies OR can be purchased directly through various medical suppliers. There is also a liquid preparation available for children who cannot swallow pills. PWSA (USA) can provide direct contact information for those families having difficulty finding a source for the liquid preparation.

