

Financial Help for Supplements

Unfortunately, many people do have problems getting their insurance company to pay for individual supplements and the mito "cocktail." But there are some ways to try to get around that. First of all, the following are some UMDF website articles which mention the general vitamins/supplements given, some of which include how physicians figure the dosages. You may want to go to the UMDF website: www.umdf.org and print out some of this information to present to your insurance company:

- 1) "Nutritional, Pharmacological and Exercise Treatment Strategies for Mitochondrial Disorders," an article by Mark Tarnopolsky, MD, PhD, FRCP(C), in *Mitochondrial News* newsletter, Volume 9, Issue 1, Winter 2004
- 2) Mito 101 document, which includes an article on supplements & nutrition by Mark Tarnopolsky, MD, PhD, FRCP(C)
- 3) MitoFIRST brochure with input from Marni Falk, MD; Sumit Parikh, MD; and Mark Tarnopolsky, MD, PhD, FRCP(C)
- 4) Think Mitochondria compendium - click on "resources for life." Then click on "UMDF Literature" and locate compendium link. Several therapy articles in the compendium explain the rationale for the use of supplements.

With your physician's help, try to determine if some or all of the vitamins/supplements in your mito cocktail are considered to be medically necessary. Blood level measurements of these components may be a useful tool in persuading your insurance company to pay for the cocktail or individual supplements because they are medically necessary, particularly if they require a prescription. Medically necessary supplements are assigned a National Drug Code (NDC) number. You should include this code when submitting the information to your insurance company. To search for codes, go to: <http://www.accessdata.fda.gov/scripts/cder/ndc/default.cfm>. Some examples of NDC numbers for specific brands of CoQ10 products can be found at: <http://lib.store.yahoo.net/lib/epic4health/NDC-Numbers-February192008.pdf> and <http://www.solacenutrition.com/products/cyto-q/cyto-q.html>.

The following website provides information regarding insurance coverage for children requiring medically necessary foods/formula in each state: <http://www.ncsl.org/default.aspx?tabid=13865>.

Coenzyme Q10, also known as CoQ10 or ubiquinone, has now been granted Orphan Drug status for rare diseases by the FDA, including mitochondrial disease. See: <http://www.epic4health.com/qcocq1incoan.html> for more information. This designation can be pointed out to your insurance company, although there is no guarantee they will pay for it. Include the NDC number with your information.

Compounding pharmacies can mix together various medications and vitamins/supplements as prescribed by your physician, particularly in liquid form. You might want to check with a compounding pharmacy to determine if your insurance will pay for the "vitamin cocktail" if it has at least one prescription drug included in it. A list of compounding pharmacies can be found at: www.iacprx.org or call 800-927-4227. At the 2010 symposium, one of the mito doctors advised us that insurance companies are "catching on" to this method of trying to get insurance to pay for all the vitamin cocktail if one prescription is included in it. They may refuse to do so. However, patients have found they are more successful in getting insurance to pay if they include one prescription medication such as Carnitor (if the patient is prescribed this by the physician; it is a prescription medication) and just one supplement such as CoQ10 together in the cocktail. One member has had success with using America's Compounding Center at: <http://www.acrx.com/>. Another compounding pharmacy that has contacted us is the Hopewell Pharmacy in NJ. They do mix the vitamin cocktails and accept insurance, and will ship elsewhere in the country. Their website is: <http://www.hopewellrx.com/> and their phone number is: 1-800-792-6670.

View this page on the UMDF website at:
<http://www.umdf.org/site/c.otJVJ7MMLqE/b.7738467/>

Our **member resources** link, accessed through log-in, includes vitamin/supplement discount information for members. (Click on "member resources" once you are on the "member home" page. Then click on the "mitochondrial disease treatment resources" link.) One of these discount sources, Solace, has a prescription version of CoQ10. It is possible that if your physician orders this prescription version, your insurance may pay for it. Solace also offers documentation for the need for CoQ10 in mitochondrial disease.

The following websites provide insurance advice:

Lots of good advice and links:

<http://www.fodsupport.org/insurance.htm>

Good links for appeals:

<http://www.familiesusa.org/issues/private-insurance/legal-rights/insurance-appeals-resources.html>

"Writing Winning Insurance Appeal Letters" from "Complex Child E-Magazine"
<http://www.articles.complexchild.com/00012.pdf>

Appeal Information:

http://www.rds.org/4/resources/when_a_carrier_says_no.htm

The following comments are from a mom who was able to get CoQ10 for her young son. Some of them could be potentially helpful, even for an adult.

Definition of Foods for Special Dietary Use

"The U.S. Food and Drug Administration, in the Code of Federal Regulations, Title 21 Volume 2 Part 105 Section 105.3, defines special dietary use of foods as the following:

- a. Uses for supplying particular dietary needs that exist by reason of a physical, physiologic, pathologic, or other condition, including but not limited to the conditions of diseases, convalescence, pregnancy, lactation, allergic hypersensitivity to food, [and being] underweight and overweight;
- b. Uses for supplying particular dietary needs which exist by reason of age, including but not limited to the ages of infancy and childhood;
- c. Uses for supplementing or fortifying the ordinary or usual diet with any vitamin, mineral, or other dietary property. Any such particular use of a food is a special dietary use, regardless of whether such food also purports to be or is represented for general use.'

When I called my insurance company I was very careful NOT to call CoQ10 a vitamin but a Nutritional Supplement as defined by FDA Code Title 21 Volume 2 Part 105 Section 105.3. Do NOT use the word vitamin but continue to call it a Nutritional Supplement like Pediasure. For those of you with g-tube fed children (like my son) I informed the insurance company that I could not just go to a local vitamin store and purchase Liquid CoQ10. I was careful to point out that the Supplement had to be special ordered through Epic4Health and because my son is g-tube fed he HAD to have the Liquid form.

Make sure that when you talk to your insurance company that you don't talk to the drug company representatives or any prescription drug plan. This is covered NOT as a prescription drug but as a Nutritional Supplement like Pediasure."

There are some pediatric charities that may provide additional financial assistance. To locate these resources, go to the UMDF National Resources Guide at:
http://www.umdf.org/site/c.otJVJ7MMLqE/b.5693171/k.93D7/Resource_Guide.htm