

Co-Enzyme Q10 Questionnaire

Co-Enzyme Q10, L-Carnitine and Amitriptyline Usage in Cyclic Vomiting Syndrome

Did you ever take co-enzyme Q10 (“Co-Q”)? (please circle answer) YES NO

If the answer is “No”, please skip all of these questions, yet answer the other questionnaires.

If the answer is “Yes”, please answer the following questions:

If you are a parent of a child with CVS, then the word “you” refers to “your child” throughout the survey questions.

1. How long did you take co-enzyme Q10 for (example: 2 months)?
2. Did you start co-enzyme Q10 and L-carnitine at about the same time? YES NO (please circle)
3. Did you start co-enzyme Q10 and anything else at about the same time? YES NO (please circle)
 - a. If “YES”, then what else did you start at that time?
4. How many times a day did you take co-enzyme Q10 (example: twice a day)?
5. What amount did you take each time you took co-enzyme Q10 (example: 100 mg)?
6. Did you take co-enzyme Q10 with food?
7. What was your approximate weight at the time that you were taking co-enzyme Q10 (example: 50 lbs)?
8. What was the name of the manufacturer of co-enzyme Q10 (if known)?
9. What formulation did you take? (Please circle all that apply): GEL CAPSULES TABLETS LIQUID OTHER (please specify):

10. Do you have Cyclic Vomiting Syndrome? YES NO DON’T KNOW (please circle)
If no, please skip to question #21
11. Prior to taking co-enzyme Q10, did vomiting episodes occur at fairly regular intervals, in response to triggers/stressors (illness, etc.) or did they mostly occur at random?
(Please circle the best response):
REGULAR INTERVALS WITH STRESSORS AT RANDOM
 - a. Did co-enzyme Q10 change this vomiting pattern? YES NO (please circle)
If “Yes”, then please circle the pattern on co-enzyme Q10 treatment: (please circle)
 - i. REGULAR INTERVALS WITH STRESSORS AT RANDOM
 - b. If you answered “with stressors,” please circle all of the triggers or stressors that you believe have triggered vomiting episodes (please circle):
ILLNESS (colds, etc.) FASTING CERTAIN FOODS EXCITEMENT ANXIETY EXERCISE OTHER (please specify): _____
12. How frequent did you have vomiting episodes prior to starting co-enzyme Q10 in the last 12 months (examples: 4 episodes a year, every two weeks, no episodes, etc.)?
13. How frequent did you have vomiting episodes while taking co-enzyme Q10 (examples: 4 episodes a year, every two weeks, no episodes, etc.)?
 - a. If you have not had any episodes since you started taking co-enzyme Q10, please check here: _____

14. How long did episodes of nausea and/or vomiting last prior to starting co-enzyme Q10 (examples: 12 hours, 4 days)?
15. How long did episodes of nausea and/or vomiting last while taking co-enzyme Q10 (examples: 12 hours, 4 days)?
16. How severe was the nausea prior to starting co-enzyme Q10 on a 1 to 10 scale, with 10 being the worst discomfort imaginable?
17. How severe was the nausea while taking co-enzyme Q10 on a 1 to 10 scale, with 10 being the worst discomfort imaginable?
18. How many times did you generally vomit during episodes prior to starting co-enzyme Q10 (examples: 6 per episode, 4 per hour)?
19. How many times did you generally vomit during episodes while taking co-enzyme Q10 (examples: 6 per episode, 4 times per hour)?
20. Do you generally have symptoms before nausea and vomiting start (“prodrome”)?
 - a. If so, what symptoms (please circle all applicable responses)? (please circle)
 BEHAVIORAL CHANGES/LETHARGY/IRRITABILITY
 CHANGE IN SECRETIONS (bowel movements, tears, sweat, saliva, etc.)
 CHANGES IN APPETITE/THIRST
 OTHER, please specify: _____
 - b. Did co-enzyme Q10 affect these symptoms? YES NO (please circle).
 If “Yes”, how?
21. Did you suffer from headaches severe enough to change your routine or cause significant distress prior to starting co-enzyme Q10?
 YES NO (please circle).
 If “No”, skip to the question #22.
 - a. How often did you have headaches prior to starting co-enzyme Q10 (examples: three times a week, once every 2 weeks)?
 - b. How often did you have headaches while taking co-enzyme Q10 (examples: three times a week, once every 2 weeks)?
 - c. How long did headaches last prior to starting co-enzyme Q10 (examples: 2 hours, all day)?
 - d. How long did headaches last while taking co-enzyme Q10 (examples: 2 hours, all day)?
 - e. How severe was the average headache prior to starting co-enzyme Q10 on a 1 to 10 scale, with 10 being the worse headache imaginable?
 - f. How severe was the average headache while taking co-enzyme Q10 on a 1 to 10 scale, with 10 being the worse headache imaginable?
22. Did you suffer from muscle cramps severe enough to change your routine or cause significant distress prior to starting co-enzyme Q10? YES NO (please circle).
 If “No”, skip to question #23.
 - a. How often did you have muscle cramps prior to starting co-enzyme Q10 (example: three times a week)?
 - b. How often did you have muscle cramps while taking co-enzyme Q10 (examples: three times a week, once every 2 weeks)?
 - c. How long did muscle cramps last prior to starting co-enzyme Q10 (examples: 2 hours, all day)?
 - d. How long did muscle cramps last while taking co-enzyme Q10 (examples: 2 hours, all day)?
 - e. How severe were the average muscle cramps prior to starting co-enzyme Q10 on a 1 to 10 scale, with 10 being the worst muscle cramps imaginable?
 - f. How severe were the average muscle cramps while taking co-enzyme Q10 on a 1 to 10 scale, with 10 being the worst muscle cramps imaginable?

23. If co-enzyme Q10 helped to relieve some symptoms much more than others, please write in those symptoms that have improved:

Please write in any symptoms that did not improve:

24. If there was an improvement after giving co-enzyme Q10, how long after starting it did you notice the beginning of improvement (examples: immediately, three months)?

a. How long after starting it did the improvement take to reach its full extent (examples: immediate, three months, still improving after 6 months)?

25. Did you have more “energy”, endurance, or muscle strength while taking co-enzyme Q10? (please circle)

YES, STRONGLY

YES

SORT OF EQUAL/NOT SURE

NO CHANGE

NO, I AM/WAS WORSE

I HAVE NOT TAKEN CO-ENZYME Q10 LONG ENOUGH YET TO KNOW

26. Did co-enzyme Q10 help with any symptom not mentioned here? If so, please list the symptoms and how it/they were helped by co-enzyme Q10.

27. Did you stop any medications because of positive effects from co-enzyme Q10? YES NO (please circle)

a. If so, please cross out the name of any treatment that you **stopped taking** since you have started co-enzyme Q10, and circle any that you decreased the dosage.

AMITRIPTYLINE (Elavil)

ONDANSETRON (Zofran)

CYPROHEPTADINE (Periactin)

SUMATRIPTAN (Imitrex)

PROPRANOLOL (Inderal)

IV FLUIDS

TOPIRAMATE (Topamax)

FREQUENT FEEDINGS

DIPHENHYDRAMINE (Benadryl)

Other: _____

L-CARNITINE (Carnitor)

28. Did you have any side effects while on co-enzyme Q10? YES NO (please circle).

If “No”, skip to question #29.

If there were more than one side effect, please answer the following questions for each side effect (separate responses by an “/”).

a. What was the side effect?

b. How long after starting co-enzyme Q10 did the side effect occur?

c. Did the side effect go away or improve substantially with time? (please circle)

YES NO STOPPED Co-Q SO I DON'T KNOW

d. Was the side effect severe or bothersome enough to cause you to stop taking co-enzyme Q10? YES NO (please circle).

e. How severe was the side effect on a 1 to 10 scale, with 10 being the worst.

29. Did co-enzyme Q10 change your stools (BMs)? (please circle)

BECAME LOOSER, WHICH WAS A SIGNIFICANT PROBLEM

BECAME LOOSER, BUT NOT A SIGNIFICANT PROBLEM

BECAME LOOSER, WHICH WAS GOOD BECAUSE CONSTIPATION IMPROVED

BECAME LOOSER AT FIRST, THEN MUCH BETTER LATER

NO CHANGE

CAUSED CONSTIPATION AT FIRST, THEN MUCH BETTER LATER

CAUSED CONSTIPATION, BUT NOT A SIGNIFICANT PROBLEM

CAUSED CONSTIPATION, WHICH WAS A SIGNIFICANT PROBLEM

30. Did co-enzyme Q10 cause you to have an unpleasant odor?
 YES, WHICH WAS A SIGNIFICANT PROBLEM
 YES, BUT NOT A SIGNIFICANT PROBLEM
 YES, AT FIRST, THEN MUCH BETTER LATER
 NO CHANGE
- a. If yes, what was the odor? FISH-LIKE OTHER: _____
31. Are you still taking co-enzyme Q10? YES NO (please circle)
 If "Yes", skip to question #32.
- a. Why did you stop co-enzyme Q10? (please circle all applicable responses)
 DIDN'T WORK WELL ENOUGH
 EPISODES IMPROVED BY THEMSELVES
 I AM ON A BETTER THERAPY, please specify: _____
 TOO EXPENSIVE
 FORGOT TO REFILL
 SIDE EFFECTS
 OTHER, please specify: _____
- b. When you stopped co-enzyme Q10 did any improvement go away? YES NO N/A, and if so, what got worse?
 i. How long after stopping co-enzyme Q10 did any improvement go away?
- c. When you stopped co-enzyme Q10 did any side effects go away? YES NO N/A, and if so, what side effects?
 i. How long after stopping co-enzyme Q10 did any side effects go away?
32. Do you believe that the improvement that you received on co-enzyme Q10, if any, justified the side effects that you experienced?
 YES, STRONGLY
 YES
 SORT OF EQUAL/NOT SURE
 NO
 NO, STRONGLY
 I HAVE NOT TAKEN CO-ENZYME Q10 LONG ENOUGH YET TO KNOW
 I HAVE HAD NO SIDE EFFECTS
33. Did insurance pay for the co-enzyme Q10?
 YES
 YES, BUT ONLY ON APPEAL
 NO, IT WAS DENIED
 DIDN'T TRY
 DON'T HAVE INSURANCE
- a. What kind of insurance? (Please circle): PPO HMO MEDICAIDE OTHER, please specify _____
34. How much a month did you personally pay for the co-enzyme Q10?
35. Do you believe that the improvement that you received on co-enzyme Q10, if any, justified the costs that you paid?
 YES, STRONGLY
 YES
 SORT OF EQUAL/NOT SURE
 NO
 NO, STRONGLY
 I HAVE NOT TAKEN CO-ENZYME Q10 LONG ENOUGH YET TO KNOW

36. Would you recommend co-enzyme Q10 to a friend or relative with CVS?
 YES, STRONGLY
 YES
 SORT OF EQUAL/NOT SURE
 NO
 NO, STRONGLY
 I HAVE NOT TAKEN CO-ENZYME Q10 LONG ENOUGH YET TO KNOW
 OTHER, please specify: _____
37. How did you hear about co-enzyme Q10? (please circle all applicable responses)
 PHYSICIAN (non-CVS specialist)
 CVS SPECIALIST
 CVSA NEWSLETTER
 CVSA WEBSITE
 CVS LIST SERVER/BULLETIN BOARD
 MEDICAL INTERNET SITE OR BOOK
 LECTURE/CONFERENCE ON CVS
 "WORD OF MOUTH" FROM ANOTHER PATIENT OR FAMILY
 RELATIVE/PARENT OF RELATIVE WHO IS TAKING CO-ENZYME Q10
 OTHER, please specify: _____
38. How was the decision to try co-enzyme Q10 made? (please circle the one best answer)
 BY MY PHYSICIAN
 JOINTLY BETWEEN MY PHYSICIAN AND MYSELF
 BY MYSELF
39. What does your physician think about your taking co-enzyme Q10?
 HIGHLY SUPPORTIVE, MY PHYSICIAN STRONGLY RECOMMENDED IT
 SUPPORTIVE, MY PHYSICIAN SUGGESTED IT
 SUPPORTIVE, BUT I SUGGESTED IT TO MY PHYSICIAN
 PARTIALLY SUPPORTIVE; TOLD ME THAT IT MIGHT HELP, BUT THAT WAS NOT LIKELY
 UNCLEAR/CONFLICTED/DOESN'T KNOW IF IT IS A GOOD IDEA OR NOT
 NON SUPPORTIVE, TOLD ME THAT IT WAS UNLIKELY TO HELP
 NON SUPPORTIVE, TOLD ME TO STOP TAKING IT
 MY PHYSICIAN DOESN'T KNOW BECAUSE I DON'T THINK THAT HE/SHE WOULD BE SUPPORTIVE
 MY PHYSICIAN DOESN'T KNOW AS IT NEVER CAME UP OR I HAVEN'T SEEN A PHYSICIAN LATELY
40. Were any other co-factors, vitamins, medications, diets or other therapies started at about the same time that co-enzyme Q10 was started? YES NO. If so, what?
41. Does anyone else in the family take co-enzyme Q10? YES NO. If so, how are they related, what symptoms are being treated, and what was the response? (please explain below)
- a. If the relative has cyclic vomiting, migraine, or muscle cramps and will complete a separate survey, please check here _____.
42. To your knowledge was a co-enzyme Q10 blood level drawn? YES NO DON'T KNOW.
 Note: Blood levels are rarely performed, so do not be alarmed if your answer is "No".
- a. If so, was it obtained on or off of co-enzyme Q10, and what was the result (example: blood drawn before starting co-enzyme Q10 and result was normal)?
43. Is there any question about co-enzyme Q10 that we should have asked but didn't (please tell us the question and your answer)?
44. Is there anything else that you wish to tell us about your experience with co-enzyme Q10?