Response of Muscular Dystrophy to Nutritional Supplementation

In January 2003, at 2½ years of age, my grandson started to show signs that were cause for concern. He was flat-footed, often losing his balance and falling, constipated and displayed an overall lack of energy. At family gatherings, most of us noticed that the boy stayed at his mother's side and didn't join in playing with his cousins. He often cried, pleading with her to carry him up the stairs. A nurse noted that he could not jump or draw a circle. However, the pediatrician saw no reason for worry at that time. During the next appointment in September, my daughter insisted that there was something wrong and the doctor agreed to order physical therapy. After a few visits to the PT clinic, the therapist requested testing, and in November, the diagnosis of muscular dystrophy was confirmed. The test results showed a CPK count of 28,000.

Upon receiving the news, I reached for my copy of *Let's Get Well* by Adelle Davis. On pages 235 and 243-245, finding evidence that nutrition had been shown to improve this disease, I visited the local health food store, and delivered to my daughter a basket filled with bottles of vitamins and other food supplements. She mixed these together, twice a day, and though not quite four years old, my grandson took them by spoon with no problem. The dosages were decided after consulting the book *Healthy Healing* (11th ed.) by Linda G. Rector and then adjusted for my grandson's size. His weight at this time was about 38 pounds and he was given:

Liquid B-complex ½ tsp 2x day
Flax Oil ½ tsp 2x day
CoQ10 (30 mg) ½ capsule 2x day
Wheat Germ Oil ½ tsp 1x day
Vitamin A (10,000 IU) 1 cap 1x day
Vitamin E (200 IU) 1 cap 2x day
Selenium (60 mcg) 1 cap 1x day
Vitamin C (500 mg.) ½ tablet 2x day
Magnesium malate (625 mg) ½ tsp 1x day
Lecithin (600 mg) ½ cap 2x day

Evening primrose oil a few drops a day

Within the first week of supplementation there were dramatic changes. He had previously been constipated and his stools were black and tar-like. That situation soon became normal and by spring of 2004, he was completely potty trained.

The days following the introduction of vitamin supplements brought a series of phone calls from my daughter, telling of incidents almost in disbelief. "I pulled up in front of the babysitter's house today, reaching in the van for the diaper bag, blanket, and toys, all the while knowing I'm going to have to pick up by son as well and carry him 6 steps up the porch and into the house. In the meantime, he had jumped out of the van, ran around it and was up the steps and waiting for me on the porch!"

His brother's cub scout meeting at the local school gym was a few days later. This evening as they often do, the siblings of the scouts were climbing up the stage stairs and jumping off rolled gym mats onto others next to them on the floor. He asked, "Mom can I go play with the kids?" She let him go and to her amazement he joined right in, up the stairs, climbed up on top of the gym mats and down off of them, running around and playing with all the other kids for quite some time.

Three weeks into the vitamins, on Thanksgiving Day, my entire family was surprised as we watched the lad and his cousin take my emptied cardboard wrapping paper rolls and use them as horses to gallop back and forth throughout the house.

Around this time he began climbing up the ladder to his brother's bunk bed. He could run, and has learned how to jump. On Easter Sunday he road his two wheel bicycle with training wheels all the way down the street, and the week following was beginning to learn how to

maneuver his sister's scooter. He displays confidence, energy, and is happy to join in and play with other children.

During his first exam 2004, at a university-based muscular dystrophy clinic, the doctors had explained that they really didn't know what type of muscular dystrophy this is, so for the time being, they labeled it Duchenne/Becker. The prognosis presented at this visit was that my grandson would be in a wheel chair by the age of seven and probably would not live beyond the age of 19. The family received no nutritional guidelines, nor any advice from the pediatrician or the university. Upon questioning these physicians about nutrition and dietary supplements, both replied, "There are no studies to indicate that diet and nutrition make a difference with muscular dystrophy."

At the second exam in May of 2005, the doctor put my grandson through a series of physical exercises and observed him running up and down the hall, getting up from the floor, checking his balance, and seeing that he could jump. Many times throughout the visit, the doctor remarked, "He is doing so good; this is great." Then the doctor examined his legs and calf muscles and said there is no sign of any hardness or stiffness there.

The doctor commented to my daughter, "What a wonderful physical therapist you must have for him." At the next regularly scheduled PT visit, she remembered to relate the compliment. The therapist replied, "Oh, I don't think it's what I'm doing; I think it's what YOU'RE doing!"

After this exam, a letter was sent from the clinic to the pediatrician that stated: "(This child) has been followed now in our muscular dystrophic clinic since January of 2004. Overall, he is really doing quite well. He seems to be gaining milestones, and not failing."

In September of 2005, my grandson was taken to the hospital for his first cardiac exam. The cardiologist told my daughter, "All that you see there is healthy and normal muscle." He had the child lie on the floor and asked him to get up. The doctor smiled as he watched, nodded his head, and said, "There is even no sign of the Gower." (Usually, because of extreme weakness of the hip muscles, a child with MD can stand up only by first lying face down, extending the elbows and knees to raise the body, then bringing them together, and finally using the arms to "climbing up" himself. This is known as Gower's sign.) The second cardiac exam was in October of 2006 and the results for both years came back the same. His heart is perfectly normal.

My grandson attended a Mental Retardation and Developmental Disabilities preschool (2004/05) and upon completion, the school decided that he was ready for kindergarten in the regular school system. In the school year of 2005/2006, the child attended all-day kindergarten. He walked to the school bus every morning at about 7:30. His classroom was located on the 2nd floor, and probably about 3 or 4 times a day he went up and down the stairs, for lunch, gym, and outside to play, and returned home at about 3:00. He joined the little soccer team after school and played a couple games a week.

The fourth annual check up at the same university clinic was in May, 2007. All four exams have been conducted similarly and concluded with the same result. The attending physician leads my grandson through a series of manual muscle tests. These include arm and leg resistance, lying down, sitting up, and lifting his legs while laying flat on his back. This time the doctor exclaimed that she was very impressed when the boy just climbed up onto the table himself. Again, the doctor stated that they were not anywhere near discussing the need for steroids. The child's weight at this time is 54 pounds. There has never

been further testing for CPK levels or any other kind of invasive testing. He finished 1st grade in the regular school system in June of 2007, participating in soccer in both the fall and spring.

For the past 4 years, my grandson has had a chiropractic spinal adjustment once per month. Some months it has been more times, but never less than one per month.He often claims that he can run faster after he has this done. He also attends weekly visits at the physical therapy clinic for children. This consists of _ hour of physical therapy and _ hour of occupational therapy. Early in 2006 the therapist noted that my grandson could now jump off a step with two feet and land on both feet. Towards the end of this last school year, my daughter noticed that when he came home from school, he began to need assistance, guiding himself using the side of the house, or reaching for her hand, climbing the steps up to their home. He sometimes places his hand on the top of each knee for guidance as he makes his way up each step, like I've seen older people do. I have seen this myself when our family gets together and there are stairs involved.

On the other hand, my house is on a hill; if you walk from the house about 100 feet up the slope in the backyard to the end of my property line it is about level with the top of the roof of my house. It's quite steep, but the boy often makes it up there all on his own and runs around with the other grandchildren.

I can't help but remember the following, which is my only other first hand experience with a child who has MD. My oldest son and his family live 25 miles from me in an apartment complex. The summer after my grandson was diagnosed, a mother and three children moved in across the street. One day, my daughter-in-law asked the mother why the middle child, a boy, crawled around the yard. He was then 6 or 7 years old, and the mother told my daughter-in-law that he had muscular dystrophy. When they first moved in, her child could pull himself up to a standing position and walk around the room holding onto furniture. Soon after that he just began to crawl everywhere. Fully aware of our success with my grandson and the supplements, my daughter-in-law shared this with the mother and she seemed interested, but said she had no money. So my daughter-in-law and I purchased the same things my grandson was taking, split the cost and she took them over with the printed documentation from http://www.doctoryourself.com/dystrophy.html .

Days and weeks followed, with my daughter-in-law inquiring about the neighbors' boy and the vitamins. The response she got was, "He doesn't like them, won't take them, and says they hurt his stomach."

Two years ago I was invited to the elementary school for grandparents' day. As we sat in the gym, the children filed in and onto the risers to prepare to sing for us. The last child to come through the doors was the boy across the street, brought in and placed next to them in a wheel chair. I'm told that he is losing the use of his hands and arms now. His mother feeds him and there are plans to get him a motorized wheel chair for this next school year.

Some years ago, my grandson expressed his dislike of the mixture of vitamin supplements, so we switched from the liquid vitamins to soft gel types. He takes them with water, all on his own. These are the supplements and dosages he currently takes:

B complex 50 mg 1x day
Flax Oil 1,000 mg 1x day
DHA/EPA 500 200 mg 1x day
Selenium 200 mcg. 3x day
A & D 10,000 / 400mg 1x day
L-Carnitine 500 mg 1x day

Vitamin E 1,000 mg 1x day
Magnesium maleate 1,250 mg ½x day
Lecithin 600 mg 1x day
Wheat Germ Oil 1,100 mg 1x day
CoQ10 130 mg, morning 30 mg, evening
Evening Primrose Oil 500 mg 1x day
Vitamin C 1,000 mg 2x day
Creatine 1,000 mg 1x day

Last week was my grandson's seventh birthday. That was the date when, the doctors originally told us, he would be in a wheelchair. My present to him was a mini trampoline that he enjoys very much.

November of 2007 will be four years since I read about the research included in Adelle Davis' book, and 35 years since its publication. Still there are no answers to explain why nutrition is not proclaimed to be the benefit that it is in treating children afflicted with muscular dystrophy.

–Kathleen M. Hanson
29418 Armadale Ave.
Wickliffe, OH 44092
kkmhanson@sbcglobal.net