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To take, or not to take, unproven supplements in the fight against Huntington's disease

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

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TUESDAY, FEBRUARY 18, 2014

To take, or not to take, unproven supplements in the fight against Huntington's disease

Should people facing Huntington's disease take creatine and other supplements to relieve or prevent symptoms?

I do.

I saw HD inexorably destroy my mother's ability to walk, talk, and care for herself. She died eight years ago this month. I tested positive for HD in 1999 and since then have worried daily about when it will strike.

There is no treatment to slow HD's devastation of the brain. So I've been open to taking supplements that might help.

In early 1996, just shortly after learning of my mother's diagnosis, I started taking [coenzyme Q-10](#) (Co-Q), a vitamin-like substance found throughout our bodies and seen by researchers as a possible way to help remedy the energy deficits suffered in HD.

In 2004, when Dr. LaVonne Goodman introduced a "treatment now" regimen and clinical trial of safe supplements that had shown promising results in animal testing, I jumped at the chance to participate. I was the only presymptomatic individual in the small, three-year study, run under the auspices of Dr. Goodman's [Huntington's Disease Drug Works](#) (HDDW).

Starting in 2005, I introduced the supplements into my diet in steps. I worked up to a daily routine in which I took 75 grams of [trehalose](#), a sugar that seems to [help the brain clear cellular debris](#); 600 mg of medical-grade [Co-Q](#); two g of [omega-3 oil](#); two g of [blueberry extract](#); and ten g of medical-grade creatine. The trial paid for and delivered the supplements.

The trial did not show significant improvement for any of the symptomatic participants. "The only thing that appeared to be helpful was trehalose," Dr. Goodman said in a February 9 phone interview. Today, almost a decade later, the supplements remain medically unproven to affect HD.

Nevertheless, scientists still think that trehalose, Co-Q, and creatine might still provide help in treating HD. Since the end of the HDDW, I have continued to take all of the supplements, spending about \$2,000 per year. In fact, several years ago, relying on medical advice, I roughly doubled my daily intake of creatine to about 20 g.

I get semi-annual blood tests to monitor potential kidney damage, which creatine can cause. I also drink plenty of water throughout the day to prevent dehydration, which can occur at doses higher than 10 g. Creatine also can cause weight gain.

Am I wasting money and endangering my health?

HD Links

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
[Huntington's Disease Advocacy Center](#)
[Thomas Cellini Huntington's Foundation](#)
[HDSA Orange County \(CA\) Affiliate](#)
[HD Free with PGD!](#)
[Stanford HOPES](#)
[Earth Source CoQ10, Inc.](#)

HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

I don't think so. A few years ago, one of the doctors at the local Huntington's disease clinic told me to stay on the supplements, observing that the combination of substances might be helping to delay my HD onset. I inherited the same degree of mutation as my mother, but, at 54, have passed the age of her onset.

The yin-yang of supplements

Whether others in the HD community should take creatine and other supplements is an individual choice ideally made in consultation with a doctor.

During our interview, the Seattle-based Dr. Goodman reviewed the pros and cons of taking creatine.

She cautioned against taking high doses of the substance, because more serious side effects occur at higher dosage, and urged people to consult a physician before starting any supplement.

She stressed that people need to understand the "yin-yang" involved in the decision to take supplements.

"Yes, you want to take care of yourself," Dr. Goodman said. If they do nothing else, supplements can at least furnish a "very important" placebo effect and the prospect of hope, she said.



Dr. LaVonne Goodman (photo by Gene Veritas)

The placebo effect is a "real" phenomenon, she observed. "If you could bottle it, it would be great."

However, taking supplements also reminds asymptomatic gene carriers of their risk, she added.

More importantly, people's use of supplements could also obstruct the path to other, potentially far more promising treatments, she said.

The benefits of supplements "need to be counterbalanced with the need to test promising new drugs, or we will never have better treatments for Huntington's," she explained.

Interfering with clinical trials?

“There are so many competing interests here,” Dr. Goodman continued. “We all want to believe that (creatine) is helpful, because it’s available, and we can take it, so why not do it, we say. This is what I said with HDDW trials. Well, yes, but it needs to be measured. Otherwise, we’re going to know nothing more than we did.”

“It is important for people to know that if they take these things, they can’t be in clinical trials at the same time. We deplete our clinical trial participant base, which is going to impede progress for finding better treatments. There’s the yin-yang. And people need to hear both.”

However, Dr. Goodman noted that individuals could do both: to become eligible for a clinical trial, individuals could clear the supplements out of their system so that they don’t interfere with the measurement of the tested drug’s effects, then resume the supplements after completing the trial.

I would stop taking my supplements in order to qualify for a trial, although until the most recent creatine trial (see below), practically every trial has targeted only symptomatic individuals.

Dr. Goodman underscored the need to treat creatine and all other supplements as “medicines.” Supplements should meet USP ([U.S. Pharmacopeial Convention](#)) standards, she added. The HDDW website contains information on supplement safety. Further information on supplements is available at [Huntington’s Disease Lighthouse Families](#).

(I buy my creatine from my local GNC outlet but plan to search for a better grade of the product.)

All drugs, including FDA-approved ones, produce side effects and can affect individuals differently, Dr. Goodman noted.

Regarding creatine, she concluded: “If it’s not watched closely, it may cause more harm than good.”

A historic trial

People in the HD community became excited about creatine as a potential treatment after Harvard University’s online news service on February 7 published an article titled [“Nutritional supplement slows onset of Huntington’s.”](#)

According to the article, a team of researchers based at the Harvard-affiliated Massachusetts General Hospital had finished a historic Phase II clinical trial that produced MRI scans showing evidence of the slowing of brain atrophy (shrinkage) in HD gene carriers who have yet to manifest the classic symptoms of the disorder. Sixty-four people took part.

Participants took up to 30 g of creatine per day.

According to Steven Hersch, M.D., Ph.D., the trial, called PRECREST (Creatine Safety and Tolerability in Premanifest HD), was a “huge step” for three reasons – including its impact on a separate creatine trial for *symptomatic* patients called CREST-E (Creatine Safety, Tolerability, and Efficacy in Huntington’s Disease)

“One, it’s the first therapeutic trial that has tried doing prevention,” Dr. Hersch, the study’s senior author and a long-time HD researcher, said in a February 11 phone interview. “Two, because we created a design that let anybody participate who’s at 50% risk, as well as those who have tested positive. And three, the imaging finding increases the probability that CREST-E will show a clinical benefit.”



Dr. Steven Hersch (photo from HDSA website)

Currently in progress and still recruiting participants, CREST-E is a phase III trial – the final step before drug approval ([click here](#) to learn how to enroll).

The PRECREST administrators recruited untested at-risk individuals who were then tested for the purposes of the trial as well as individuals who already knew that they have the HD mutation. However, those who entered the study untested did not receive their results, which were only known to the statistician. Thus, they avoided the potentially traumatic psychological aftermath and remained protected from genetic discrimination.

“The ethical challenges for those recruiting and conducting trials include how to accommodate nontested at-risk individuals while preserving a noncoercive choice regarding genetic testing,” states an editorial about PRECREST in the March 2014 issue of the prestigious journal *Neurology*, adding that “unequivocal changes” occur in the brain of presymptomatic individuals “15 to 20 years before conventional clinic-based diagnosis.” An article on PRECREST by Dr. Hersch, lead author Herminia D. Rosas, M.D., and nine other collaborators appears in the same issue.

For these and other reasons, 90 percent of at-risk individuals choose not to test, Dr. Hersch explained.

The MRI changes and other data from PRECREST will eventually be assessed in CREST-E, Dr. Hersch explained. CREST-E is also doing MRI imaging. With nearly 600 participants so far, it will be large enough to show whether the benefits shown in PRECREST images correspond to a significant slowing of HD.

Avoiding false hopes

As with many news articles about clinical trials and other scientific experiments, the Harvard report’s headline, which claimed the supplement slowed the onset of HD, inaccurately reflected the researchers’ results as reported in the actual scientific article.

“While slowed atrophy suggests that creatine could slow preclinical progression, the potential clinical impact of these findings on delaying the onset of HD is unknown and must be defined by an efficacy study designed to measure it,” the *Neurology* article states.

Nor can the public buy the high-quality creatine used in the study, as it’s prepared specially for clinical trials.

"I don't want people to take from this study that they ought to go running out and take a bunch of creatine or take it at these doses," said Dr. Hersch. "Even though the imaging benefit is very exciting, we don't know what it means clinically. It doesn't provide the evidence that would lead me to recommend that people take it. The high doses that we used should also not be used without medical supervision."

As noted in the *Neurology* article, some PRECREST participants suffered stomach upset and diarrhea caused by the creatine. About a dozen people had to drop out of the study.

Regarding the study's clinical significance, Dr. Goodman offered an assessment similar to that of Dr. Hersch.

The widely read HD research website HDBuzz.net also weighed in.

"How much hope and how my hype?" an [HDBuzz article](#) asked. While recognizing the importance of the study, it pointed out that the causes and effects of the slowed shrinkage in the brains of the PRECREST participants need further study.

"It's possible that creatine causes HD brain cells to bulge or swell without making them healthier," it states. "Swelling like that could produce false optimism and might even be harmful. That's not something this trial can tell us either way, because the patients weren't followed long enough to see whether creatine treatment delayed the onset of symptoms."

"The participants in PRECREST who took creatine but did not have the HD mutation did not experience any brain swelling, so this is an unlikely explanation for our findings," said Dr. Hersch. "Including and treating these subjects was very unusual. However, we did so to allow us to answer questions like this."

Awaiting the Holy Grail

"HD researchers face a major challenge in finding a treatment for the pre-manifest," [I wrote](#) in 2011. "It's really the Holy Grail not only for HD, but also for other neurological diseases such as Alzheimer's in which brain damage occurs many years before symptoms appear. Ideally, researchers want to design medications that will completely prevent these diseases."

The *Neurology* editorial used the term "Holy Grail," too, in noting how the PRECREST study "investigates a potentially neuroprotective agent designed to delay disease onset."

The word "potentially" is key.

As Dr. Hersch explained, the PRECREST findings about slower shrinkage "suggest" that creatine provides a benefit, but they don't permit researchers to say anything about delayed onset of symptoms in presymptomatic individuals or a longer lifespan for patients.

It remains for the CREST-E Phase III trial to produce similar brain scan results – *and* an actual effect on symptoms.

"If CREST-E shows efficacy in slowing down the disease in people who are symptomatic, I would think that most people would think that you may be slowing down the disease in people who aren't symptomatic yet as well," he said.

Until treatments become available, presymptomatic gene carriers like me will continue to face the extremely difficult decision about whether to take supplements.

I'm grasping at creatine and other supplements in the hopes of delaying onset until researchers succeed.

Posted by [Gene Veritas](#) at [11:18 PM](#)



Labels: [atrophy](#) , [brain](#) , [clinical trials](#) , [creatine](#) , [CREST-E](#) , [Harvard](#) , [Huntington's disease](#) , [kidney](#) , [Neurology](#) , [onset](#) , [PRECREST](#) , [premanifest](#) , [presymptomatic](#) , [Steven Hersch](#) , [supplements](#) , [symptoms](#) , [treatments](#)

8 comments:

 **Anonymous said...**

I am at risk and have taken creatine on and off for sports/performance reasons. I realize how expensive it is. If you don't mind me asking, approximately how much do you spend on supplements for HD? Thanks

[12:13 PM, February 19, 2014](#)

 **Anonymous said...**

Have you considered therapeutic marijuana?
<http://www.psychologytoday.com/blog/all-about-addiction/201102/thc-huntingtons-disease-cb1-receptors-important-more-drug-use>

I am at risk and take a few inhalations every evening for the same reasons you take supplements. It took me a while to forget my preconceptions about marijuana and realize that all of the drugs and supplements are chemicals like marijuana. It also helps me relax and not overthink my situation.

[12:23 PM, February 19, 2014](#)

 **Anonymous said...**

Thanks for your foray into the bewildering maze of supplements. I find myself wishing for some authoritative voice that would say to either take them or not, but of course science is not there yet.


[6:04 AM, February 20, 2014](#)



 **Gene Veritas said...**

@ "I am at risk" I spend about \$2,000 annually on supplements. I linked the supplement names to vendors. Thanks for reading and commenting on the article.

[2:38 PM, February 20, 2014](#)

 **Steve said...**

Thanks your your information Gene. I recently found your blog through a link from newsHD.net. I am at risk but decided not to get tested, primarily because there is not much I can do if I did have it. Now I am giving that a second thought. \$2000 is a lot of money if I don't have it, but its peanuts if I do have it and these supplements can give me a few more quality years.

Where/how do you get medical grade creatine? I have only

seen the GNC and Twin lab buody building stuff. The recent article about creatine showing promise for HD made me wonder about the quality of the body builder stuff.

6:42 AM, February 21, 2014



Gene Veritas said...

I don't know how to get medical grade creatine. The creatine from the CREST-E and PRECREST trials is not available to the public. GNC brand is not USP. I was at Whole Foods tonight; the creatine they sell is made in a GMP (good manufacturing practices) facility in Germany. It's more expensive than GNC. It's important to use supplements that don't have impurities. Anybody can get e-mail updates of my blog. Send me an e-mail at curehdnow at earthlink do net.

10:52 PM, February 21, 2014



Gene Veritas said...

curehdnow at earthlink dot net

10:53 PM, February 21, 2014

Anonymous said...

Did you take it as tablets? 2 grams of omega3 means real 2 gram of drug (4 * 500 mg for example of suplement) or more but you calculate bioavailability? the same concerning creatine? Currently it is heard that 1000 mg of Co-q is desired. Could You comment? thanks jakbysiedalo

5:41 AM, February 22, 2014

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