

hi folks,

several people have asked about my health, so let me give a brief rundown on the situation.

the condition i have is called RNase Enzyme Deficiency Disease (i love the acronym: REDD). it is thought to be either fully or partially responsible for a host of illnesses, including multiple sclerosis, myalgic encephalomyelitis, ALS, inflammatory rheumatoid arthritis, Gulf War Syndrome, fibromyalgia, to name a few.

for a long time its contours were unknown, but there is now a definitive test (95% positive) and it is considered a discrete, well-defined clinical entity, although accurate information about it is rare, especially among physicians (to the extraordinary detriment of their patients).

the basic problem itself is straightforward: RNase is an enzyme produced by the human body when it is attacked by viruses or bacteria. as the name implies, RNase denatures messenger RNA wherever it find its. as it comes in contact with the invading virus or bacteria, it destroys its RNA and thus kills the bug. this is a very quick-acting defense mechanism, unlike the slower production of T cells, B cells, etc., which can take days or even weeks, and thus is one of the body's first lines of defense.

in REDD, the mechanism that produces RNase is damaged by any number of causes, the most notable being environmental toxins. in 1985, in incline village, north lake tahoe, there was what has now become a very famous outbreak of REDD, where over 200 people came down with it within a few months (i was one of the lucky 200. treya and i were in tahoe recovering from her latest round of intensive chemotherapy). a widely circulated hypothesis is that it was triggered by a local toluene spill, but nobody really knows. the disease itself, however, is not human-to-human transmissible.

once the damage is done, the body begins producing a shortened but highly active form of RNase (37 kD instead of 80 kD). this 37 kD RNase has no turn-off mechanism, because the body only recognizes the 80 kD forms. therefore, after it has killed the invading virus and bacteria, the body keeps producing this 37kD RNase, which proceeds to go through the body and attack its own RNA in literally every cell in the body.

the test for this 37 kD RNase is positive in 95% of the patients identified with REDD, and 0.00% of the population at large, which is why it is considered a definitive test and a definite clinical entity.

one of the first things damaged by this defective RNase is the glutathione system, which is one of the body's major anti-oxidant systems. this leaves the body open to serious damage by its own free radical cascades. the areas most damaged are those that produce the most energy and free radicals, namely, the mitochondria, the small organelles in cells that produce all of the body's energy.

as the condition progresses, more and more mitochondria are damaged and destroyed. in severe cases, the person is bedridden for the rest of their lives. many of the tahoe victims are still bedridden. that means literally, with around the clock professional care.

another system quickly damaged is the body's Th1 immune system, which is responsible for intracellular protection (i.e., protection against pathogens that attack inside the cell, like viruses and primitive bacteria such as mycoplasma). an opportunistic bug is defined as one that is

already present pretty much everywhere (and is already crawling all over you), but only attacks when a portion of the immune system fails. in the case of REDD, the opportunistic viruses are hhv6, epstein barr, and CMV; and on the bacterial side, mycoplasma. over 70% of REDD patients have active hhv6, and over 75% have active mycoplasma infections. for the population at large, it is less than 1% for both of those.

those are the symptoms common to all forms of REDD. additional symptoms vary depending upon which other systems are hit hardest by the body's own free radical cascades. if brain tissue, the result is myalgic encephalomyelitis, functionally indistinguishable from MS (and MS also patients have >60% active hhv6 and mycoplasma). crippling forms of chronic fatigue, rheumatoid arthritis, Gulf War syndrome, and ALS have been linked to this cluster.

the first phase of the illness lasts about 5 yrs, and comes to an end, ironically, when the body's capacity to synthesize protein is so badly damaged that it can no longer make any RNase, either. the person then enters a second phase, which last about ten years, where things are relatively quiet in terms of the illness itself, it's just that their physical activity is severely compromised and they live in what has been called a "functional bubble," often having only a few hours a day of walking-around time. fortunately, i had cultivated a lifestyle that never required a body (:-), so i had a pretty good middle ten years (roughly, all of the 1990s).

the third phase begins when the cumulative damage to various tissue systems starts to take a toll. basically, it just opens the body up to new attacks by the 37 kD RNase. every time you get an infection, cold, flu, or fever, your body produces interferon, which tells cells to start producing RNase—which in this case is, of course, defective. so more mitochondrial damage, etc.

the basic symptom is "hypoxia," or lack of oxygen in the cells (due to damaged mitochondria), so you feel like you are suffocating most of the time, and you're often bedridden around the clock (literally cannot stand up). also fortunately for me, this means mega meditation. it also means depression, sadness, and pain, not so much for the pain in this body, but the pain of what this body can't do.

weirdly, of course, my spirit-mind just keeps writing books, and during this last really severe period (the last half year), i managed about 800 really good pages. often written in bed, but no matter.

the central issue for me has never been the mitochondrial damage per se, which i have always been able to handle fairly well, although it was nonetheless a total pain. (interestingly, REDD damages the aerobic system, and not so much the anaerobic system—which is why, although i didn't know it at the time, i stopped jogging and starting weight lifting....)

the central issue has been instead when i get one (or two or three) of the opportunistic infections on top of the REDD. think of the worst case of flu you've ever had, subtract 80% of your energy, and that's sorta what it's like—but fortunately it only lasts for 6 or 8 months.....

much of this information (including the existence of the 37 kD RNase, extensive mitochondrial damage, the 70+% infection rates with hhv6 and mycoplasma) has only been discovered in the last 5 years or so, which is why i previously didn't talk about it per se—i didn't know "it" was an it. i simply handled whatever it was and went on about my dharma.

some of you remember the really bad staph infection i had about 5 years ago. i did indeed have a staph infection, and at the time it appeared that was the culprit. but that never really made total

sense, no matter what the doctors said, because staph doesn't cause those types of symptoms. looking back on it, it is now virtually certain that i had opportunistic mycoplasma (which can be killed by 6 to 12 months of dual antibiotics—the same antibiotics they coincidentally but fortunately put me on for the staph infection). so the reason i got better after about 8 months of antibiotics was not because it killed the staph, but the mycoplasma.

at any rate, starting last spring i began running a chronic fever, which really put me down in a rather unpleasant and prolonged fashion, with mitochondria croaking by the buckets full and me on oxygen (a very cool trip). i am now two months into a 6 month or longer course of dual antibiotics.

as it turns out, there are now tests for all 6 of the major opportunistic bugs that come along for this ride. my problems have always been when one of those is added to the REDD. so in the near future i will undergo tests for all these, so i can knock the little shitheads off one by one. compassionately, of course.

as for what specifically triggers the damaged RNase, nobody knows, although environmental toxins are a leading factor. i learned from a researcher last week that harvard thinks they found a retrovirus. if so, that's the most likely culprit. it's still not human-to-human transmissible, so i personally hope there is retro virus, since that would mean that there is at least the possibility that an hiv-like protease inhibitor cocktail could attack the actual cause of the illness. but we shall see....

(let's pause for a fun one-minute rant: do i spend much time worrying about the "lesson" i am trying to teach myself by giving myself this illness? go fuck yourself. answer the question? treya and i spent 5 years listening to people telling her why she got cancer. all of them were telling her what she had spiritually done wrong in order for this to happen. problem is, none of them really agreed with each other, and only thing they had in common was a particular person's arrogant assumption that they knew what was really moving treya, or their deep fears projected onto treya and read back to her as the cause of her cancer. of course there are spiritual, mental, and emotional factors in all illness. if you want to know what mine are, ask me, don't tell me. if i want to know your opinion, i promise i will ask. otherwise, keep your projections to yourself, because i already have one asshole to deal with.)

you can tell anybody you want about this illness, it's not confidential or anything. once i found out what it was, i've never kept it secret—although i often just say "it's that old staph infection," because the real story takes too damn long to explain.

sometimes i do well with it, sometimes not. much of the time i am fortunate, and there is radiant sahaj, with a painful body spontaneously arising in an ocean of blissful emptiness. at other times, there is just the painful body. in all cases, my I is free and radiant, but my me is fucked, and it's just a matter of which side of the identity street you want to play on.

what is not great is the physical things that i cannot do during active infections—which is why we had to call off the integral psych seminar and the ITP seminar. those things are by far the hardest for me to bear, not being able to do that. i sometimes just think of this thing as a war wound i got when taking care of treya, and somehow that makes it easier to bear. but again, in so many ways i am extravagantly blessed beyond anything deserved—this mind intersects God's every and now and then, and even the angels weep.

thank you all very much for your kind wishes, prayers, taking and sending, and caring regard. honestly, when i rest as I-I, i am Free and Full, i promise you. physical bodily life is not so great, however, and i won't lie about that. it is sometimes more than i think i can bear. but right now i have everything i need, willow and the ii interns are here to help, marci is doing industrial strength reiki on me, and things are as they as they are, always.

i have been writing up a storm. i finished vol 3 (now vol 2) of the kosmos trilogy—about 1200 pages or so in all, which i will edit and hopefully condense a bit (or hell, just arbitrarily break it in two and put “volume 2” on the first pile and “volume 3” on the second). the last half of it will be appearing in a series of excerpts, of which excerpt A is already posted. but while i was editing excerpt B, i got sidetracked into this thing on perspectives that i mentioned to some of you. it's really outrageous, easily as cool as the SES stuff. in fact, just like with SES, i now have yellow legal pads all over the place with the beginnings of an “integral calculus” on that constructs a kosmos with perspectives instead of perceptions. part of it is an actual calculus, like g spencer brown's laws of forms (which varela used in his autopoiesis theory), except brown used a flatland cosmology where subjects see objects, instead of first and second and third persons (holons) seeing each other. the latter gives you a real kosmos with real sentient beings having perspectives, not an agent starrng blankly at a world of alien communions. part of this theory also includes an actual integral calculus (mathematics) that is totally fucking mind blowing. anyway, i'm up to 120 legal pad pages, so maybe when i hit 200 it will be fleshed out. so far it has generated holons, quadrants, levels, lines, semiotics, systems theory.... david deida was here visiting the last few days, and he got a pretty good overview of it. he definitely thinks it's beyond SES.... ask him about it. (if he tells you he was humoring the sick guy, keep it to yourself.)

anyway, fortunately i only need a two fingers to type, so physical limitations haven't hurt me too much in that regard. and i have been putting in several hours a day with ecoisp—bob and tom are good enough to come over to the loft. the rest of the day, mostly in bed, meditating or agitating, depending.

needless to say, i hope that the combination of testing and treatments will get the opportunistic bugs under control. if so, i can resume a more active physical life, including meeting with core teams, i hope. if not, not. will keep you posted.....

much love, ken