








# Summary Report

(Completion rate: 100.0%)







I have been diagnosed with (check as many as apply)

Response	Chart	Percentage	Count
Chronic fatigue syndrome (ME/CFS)		83%	67
Fibromyalgia		54%	44
Irritable Bowel Syndrome		30%	24
Migraine		16%	13
TMJ (temporal mandibular syndrome)		14%	11
Ehlers Danlos Syndrome		5%	4
Other, please specify...		26%	21
Total Responses			81











I have been diagnosed with (check as many as apply) (Other, please specify...)

#	Response
1.	lyme
2.	Orthostatic Intolerance
3.	Sjogrens, Post-Polio Syndrome
4.	hashimotos
5.	seizure disorder
6.	Hyperadrenergic POTS, Hashimoto's (an autoimmune thyroid disease)
7.	
8.	
9.	Bipolar Type II
10.	POTS, MCAS, hypogammaglobulinimia, meningioma, vitiligo, alopecia, Chronic Kidney Disease, Protozoa and co-infection, Spondylitis, Osteoarthritis, Meningoma
11.	Osteoarthritis . Epilepsy of old age
12.	Osteoarthritis
13.	Insomnia, POTS
14.	POTS
15.	diabetes, osteoarthritis, prolapsed discs in lower back, fused discs in neck, depression, anxiety
16.	Meniere's, Lyme, UMN Bladder,
17.	lyme disease
18.	Immune dysfunction
19.	Hypothyroidism
20.	Type 2 diabetes
21.	FM 23 years




I have had ME/CFS or Fibromyalgia for 'X' number of years. (Please use the disorder you've had for the longest amount of time to answer this question.)

Response	Chart	Percentage	Count
I year or less		1%	1
1-2 years		4%	3
3-5 years		11%	9
6-10 years		18%	15
11-20 years		20%	16
>20 years		46%	38
Total Responses			82





Based on a scale from 1-10, ten being in perfect health, how healthy would you say you are right now.

Response	Chart	Percentage	Count
1		2%	2
2		17%	14
3		24%	20
4		17%	14
5		13%	11
6		16%	13
7		7%	6
8		2%	2
9		0%	0
10		0%	0
Total Responses			82

Your degree of clarity with regards to high-dose B-1 effectiveness

Response	Chart	Percentage	Count
I feel clear about whether high-dose B-1 will be effective for me		26%	21
I'm pretty sure about B-1's effectiveness but will experiment a bit more		44%	35
I'm not clear about how effective B-1 will be for me; I'll take the rest of the survey later		32%	26
Total Responses			80

## How long have you been taking high-dose B-1?

Response	Chart	Percentage	Count
1-3 days		15%	12
4-7 days		23%	18
> 1 week		47%	37
Other comments		14%	11
Total Responses			78







## How long have you been taking high-dose B-1? (Other comments)

#	Response
1.	Took 100mg one time, produced energy, extra activity resulting in severe headache relapse
2.	3 days each: 500, 750, 1000, 1250
3.	I Ordered thiamine after reading Karen's blog- So I will report back on the survey in about a week
4.	previous question makes no sense...but I'm taking the rest of the survey now if you don't mind
5.	I guess I have not really got to a high dose yet
6.	current dose 600mg
7.	very slowly for 2 weeks
8.	dont take everyday,yet
9.	Took my first one today.

## EFFICACY - please do not vote on a dose you haven't tried for at least three days

	major improvement	somewhat better health	no change	somewhat worse health	much worse health	Total Responses
300 mgs/day	2 (7%)	5 (19%)	18 (67%)	1 (4%)	1 (4%)	27
500 mgs/day	0 (0%)	10 (34%)	17 (59%)	2 (7%)	0 (0%)	29
600 mgs/day	1 (4%)	8 (29%)	18 (64%)	1 (4%)	0 (0%)	28
900 mgs/day	2 (12%)	5 (29%)	10 (59%)	0 (0%)	0 (0%)	17
1,000 mgs/day	1 (4%)	7 (28%)	14 (56%)	3 (12%)	0 (0%)	25
1,200 mgs/day	3 (18%)	3 (18%)	7 (41%)	4 (24%)	0 (0%)	17
1,500 mgs/day	1 (7%)	2 (13%)	8 (53%)	4 (27%)	0 (0%)	15
1,800 mgs/day	2 (33%)	1 (17%)	2 (33%)	1 (17%)	0 (0%)	6
>1,800 mgs/day	0 (0%)	0 (0%)	2 (67%)	1 (33%)	0 (0%)	3

**SIDE EFFECTS - If you experienced any side effects please tell us how strong they were**

Response	Chart	Percentage	Count
No side effects		59%	41
mild side effects		20%	14
moderate side effects		10%	7
strong side effects		6%	4
please state what they were		36%	25
Other comments...		10%	7
Total Responses			69

**SIDE EFFECTS - If you experienced any side effects please tell us how strong they were (please state what they were)**



#	Response
1.	unable to sleep
2.	I am waking every 1.5 hours during the night - a side effect or just the fibromyalgia?
3.	tired
4.	possible increase in insomnia
5.	headache, felt ill waited a day, cut the pills in half and tried that, after 3 days still felt ill and had head pain
6.	Very slight queasiness
7.	
8.	Daytime sleepiness
9.	More pain Don't know..so hard to tell. Feeling worse than before started b1 but don't know if that's a coincidence
10.	Itching
11.	mild, short term headache at 1000 mg
12.	with higher dose - over stimulation of sympathetic system
13.	In bed by day 3 with nausea worsening CFS fibro; had to stop taking. On day 1 I thought there was a bit of improvement in my chronically low energy levels but it didn't last.
14.	made me drowsy - had to sleep
15.	Headache and dizziness
16.	Nausea bordering on vomiting
17.	deterioration of cfs symptoms
18.	Very woozy...
19.	Too high dose (1200 mg) increased my overall ME-symptoms: Tachycardia, pain, sleep problems, PEM.
20.	when I started my blood pressure dropped, but I have increased my B12 to 2500mcg Side effects are less now

21.	feeling sick and light headed on higher dose
22.	insomnia
23.	jittery
24.	Upset stomach and indistion at 1200mg, but went away after a couple of days
25.	@ 1000 and @1500 mgs/day, I felt more fatigue and nausea





SIDE EFFECTS - If you experienced any side effects please tell us how strong they were (Other comments...)

#	Response
1.	Took 100mg, gained more energy, did more, developed severe head muscle pain for a week, bedridden bcs of overdoing
2.	headache, felt ill waited a day, cut the pills in half and tried that, after 3 days still felt ill and had head pain
3.	
4.	More pain Don't know..so hard to tell. Feeling worse than before started b1 but don't know if that's a coincidence
5.	In bed by day 3 with nausea worsening CFS fibro; had to stop taking. On day 1 I thought there was a bit of improvement in my chronically low energy levels but it didn't last.
6.	higher dose made CFS MUCH worse and I had to go down to small dose where i felt major improvement
7.	when I started my blood pressure dropped, but I have increased my B12 to 2500mcg Side effects are less now

If you experienced any side effects did lowering the dosage stop the side effects

Response	Chart	Percentage	Count
Yes		50%	13
No		50%	13
Total Responses			26

NEXT STEPS - Please are you planning to continue taking or experimenting with high-dose B-1?

Response	Chart	Percentage	Count
will continue to take		46%	34
will continue to experiment		53%	39
not planning to continue either taking or experimenting		9%	7
not sure		7%	5
Total Responses			74

Any other comments...

The 31 response(s) to this question can be found in the appendix.

## Appendix

Any other comments... |

#	Response
1.	Vascular headaches muscle pain are the result of having energy doing even a little more than usual. B1 gave me energy I felt compelled to do housework, not a lot but more than usual. I developed severe head muscle pain as I always do was bedridden bcs of the pain for a week. So, even if I have energy, pain is the result of activity. Haven't tried lowering dosage bcs I'm still coping w/migraine type head pain. The more I do, the worse it gets.
2.	I plan to stay at the 2000mg dose for a full week then got to 3000mg for a week. I'll stop if still no improvement.
3.	I have more energy but my stamina level is so low I have to be very careful not to overdo. Pain level has not diminished. I will continue to increase the dosage and see what happens.
4.	I've only been taking this for 4 days, and I'm not sure if it's contributing to trouble falling asleep. Also I want to try 1500 mg and see if my energy improves even more.
5.	I SO wanted some results from this.
6.	Keeping close track of changes
7.	I haven't had enough time on B1 to tell yet if it's effective. I do seem to have a somewhat higher level of energy, but it IS summer when I usually improve anyway. Stay tuned!
8.	Dosage is for a 12 year old, 50kg boy. Has had his best week in many months. He's not sure its the thiamine, but the timing is kind of uncanny!
9.	No noticeable improvement
10.	At first thought more energy. upped dose gradually but felt worse. May have overdone but not sure. But have had more bad days than usual. I only weigh 93 lbs. Wonder if dose too high? Will stay at 600 mg. for a while.
11.	Less meds, more supplements no increase in pain
12.	I've read that regular B1 often has no effect and that one should take Benfotiamine instead. I may try taking that if 1500 mgs of B1 does nothing for me.
13.	None
14.	Makes sense that this could be effective. If one has a diet that is high in B1 - maybe, won't need as much in a supplement form. My diet is high in B1 and therefore - I only take it a few times a week.
15.	I've had this kind of experience over over again; my body just won't tolerate chemicals or big doses of anything.
16.	I increased dosage too quickly. Going to go slow now and see how it goes.
17.	what's the difference between "will continue to take" and "will continue to experiment"?
18.	my cfs had improved from severe to relatively mild over the seven years since onset. 300 mg had an immediate and pronounced negative impact; I stopped taking after 5 days and returned to previous (relatively) decent condition.
19.	Actual current dose is 750 mg
20.	okay, i have to ask why EDS (Ehlers Danlos) was listed in the first question; it's not super common and i've never seen any link between cfs and eds. do you know something i don't??!
21.	I was worse on dosages suggested and improved on small dose of 300 mg
22.	At least it's cheap!
23.	It makes sense to many that ME CFS could cause a Thiamine defeciency over time.

- 
24. I'm experimenting with high dose B vitamins, all of them, not just B1, but thanks soooo much for the information I have been taking b complex for awhile very disappointing, because (I'm hoping!) I wasn't taking enough, but now I am hopeful.
- 
25. I am trying a few drops of liposomal glutamate as well, tried 1tsp and had a lot of head pressure and felt stressed, but taking the smaller dose with the B's and I feel more relaxed
- 
26. have stopped for two days to see if any crash in energy or pain, none as of yet, just back to as I was prior to experimenting with b1. will begin again today or tomorrow.
- 
27. much better energy with slight decrease in pain
- 
28. thank you Cort , the minute the first post came out I ordered and tried... and Ive been feeling much better... unless it's a coincidence b-1 actually does help...
- 
29. A day after I started the B1 I got a complication of high glucose(550 range 65-99) that must be treated but I refused to give up the B1 so the info is a bit muddled.
- 
30. I have gone from only managing 1500 - 1700 steps a day to now being able to take 13,000 steps a day. Plus I've been able to take part in activities that I haven't been able to do in nearly eight years! I seem to be improving everyday
- 
31. My fibro is not as severe as many experience, but I can definitely tell a positive effect at 500 mgs. I may try to increase more slowly than every 3 days as that seemed too fast for my body.