

## Updated Results – High-Dose Thiamine Survey among people with ME/CFS, EDS, and Fibromyalgia

March 19, 2023

These are the final results of the survey on the use of high-dose thiamine by people with ME/CFS, EDS or Fibromyalgia. Results for the first 55 respondents are published here:

<https://www.healthrising.org/blog/2021/06/02/fibromyalgia-chronic-fatigue-syndrome-benefit-high-dose-thiamine/> . Please see the article for a full description of the figures. Researchers that wish to access the data may contact Jeffrey Lubell at [jefflubell@gmail.com](mailto:jefflubell@gmail.com) .

In all, a total of qualifying 108 respondents shared information about their experiences with high-dose thiamine, which was defined as 200 mg or more of daily use of any form of thiamine.

Figure 1 records the share of qualifying respondents that reported a large or small improvement, no improvement, mixed results, or a worsening of their symptoms.

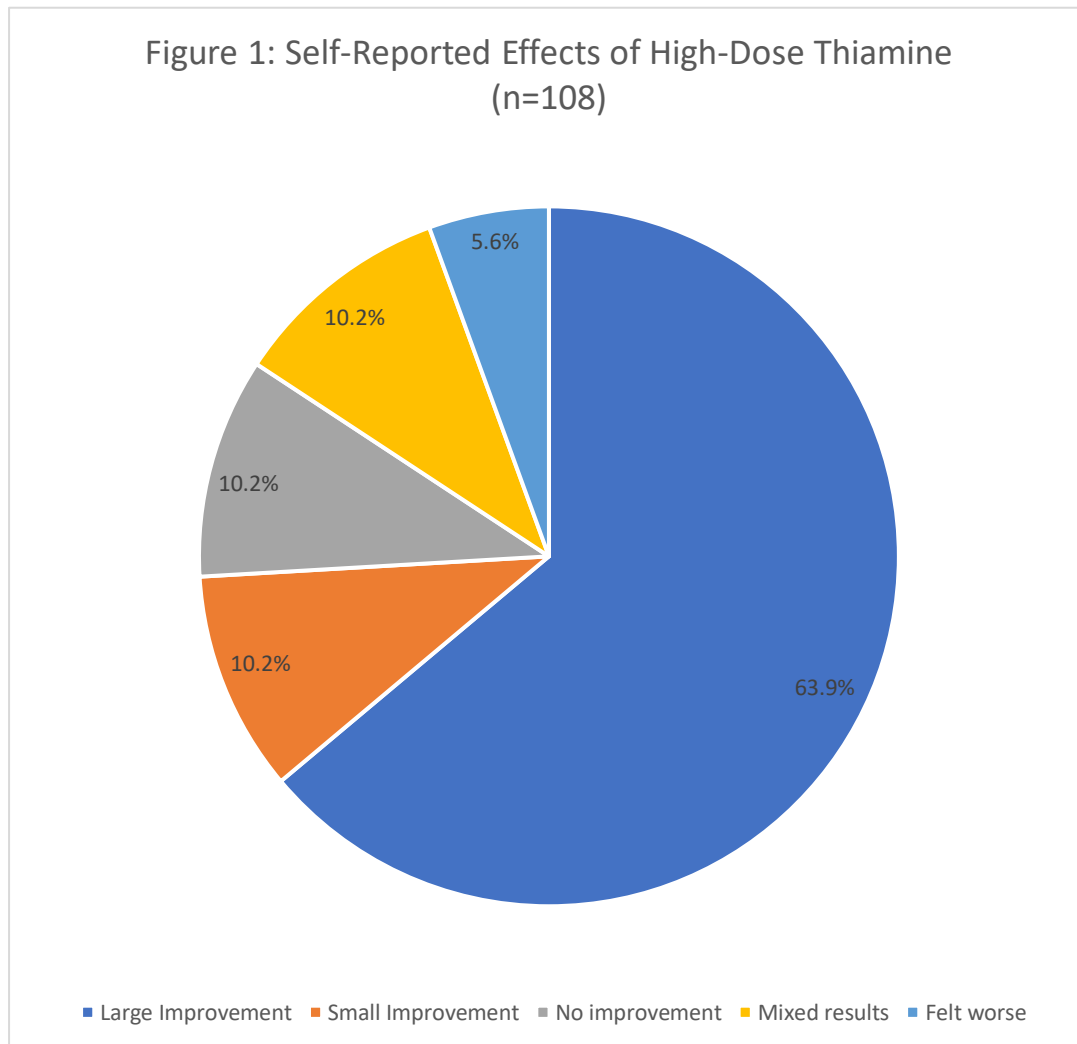


Figure 2 shows the number of respondents that reported a range of improvements. Since brainfog was only added midway through the study, an adjusted total is provided that applies the proportion of respondents citing an improvement in brain fog to the entire sample size.

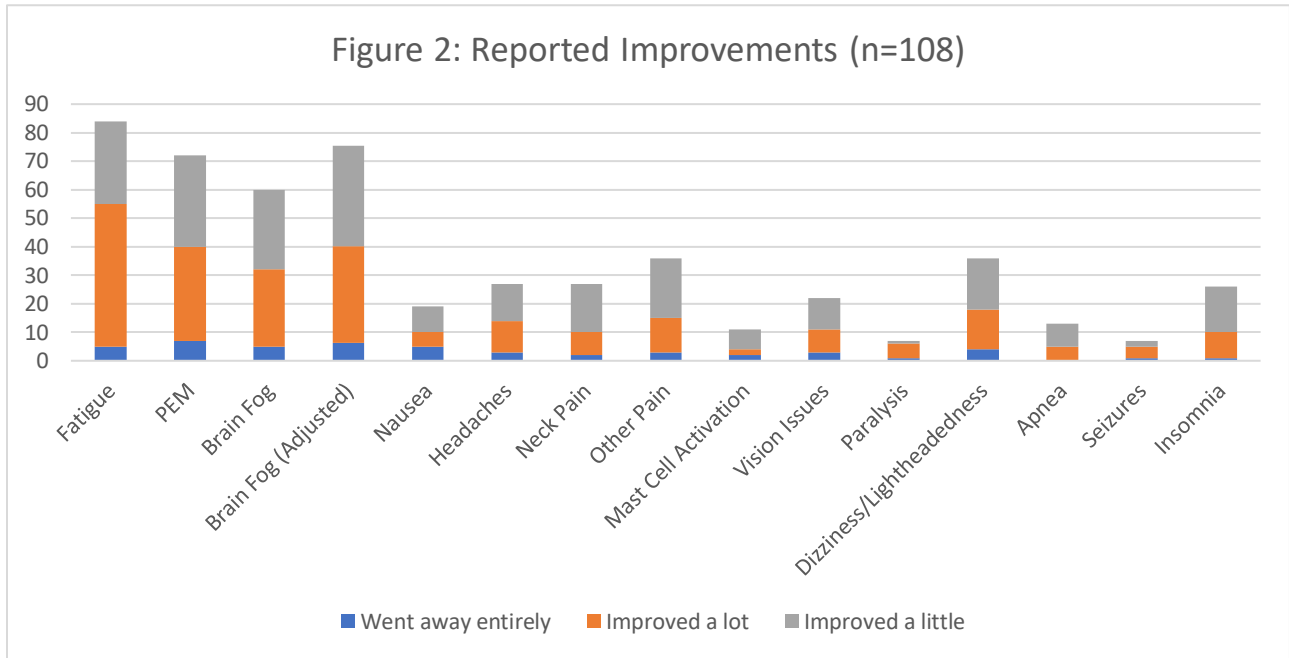


Figure 3 show the number of respondents reporting feeling worse on these same dimensions.

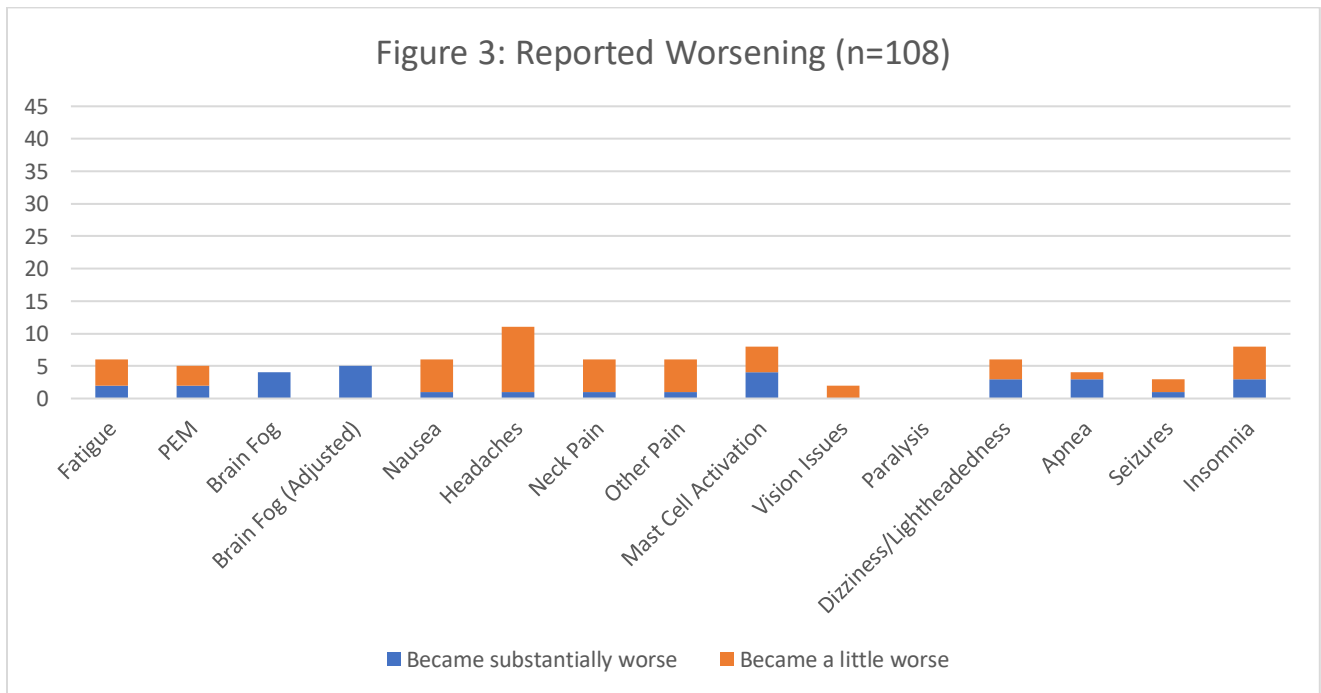


Figure 4 shows reported side effects.

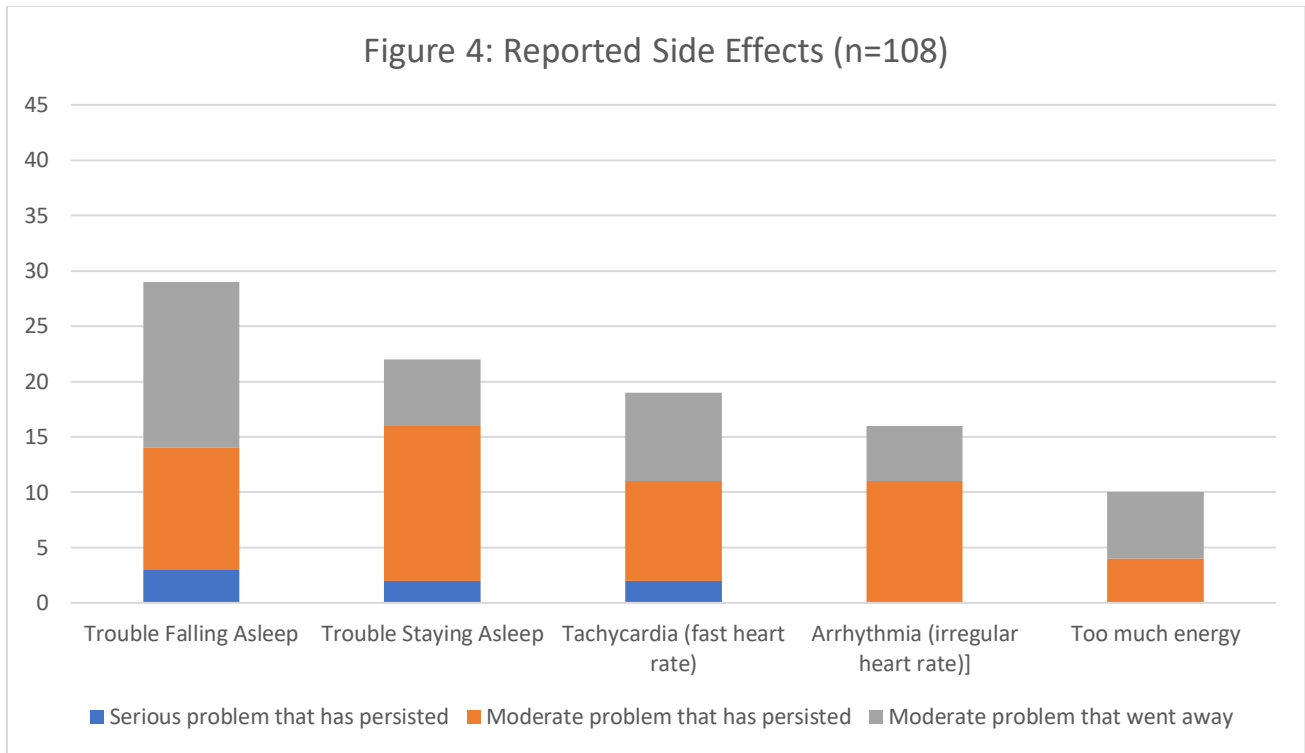


Figure 5 shows results by reported condition.

	Number	Improvement	No Improvement	Mixed	Worse
<u>Overlapping Categories</u>					
ME-CFS	97	73.2%	11.3%	9.3%	6.2%
Fibromyalgia	38	73.7%	5.3%	15.8%	5.3%
Ehlers-Danlos Syndrome	20	60.0%	5.0%	20.0%	15.0%
MCAS	27	66.7%	7.4%	18.5%	7.4%
POTS / Dysautonomia	53	62.3%	13.2%	18.9%	5.7%
<u>Exclusive Categories</u>					
Ehlers-Danlos Syndrome	20	60.0%	5.0%	20.0%	15.0%
Fibromyalgia but no EDS	26	84.6%	3.8%	11.5%	0.0%
ME/CFS without EDS or Fibromyalgia					
With POTS	26	61.5%	23.1%	15.4%	0.0%
Without POTS	33	81.8%	9.1%	0.0%	9.1%

Figure 6 shows results by reported daily dose.

	Number	Improvement	No Improvement	Mixed	Worse
200-499 mg	36	69.44%	5.56%	19.44%	5.56%
500-600 mg	28	71.43%	10.71%	7.14%	10.71%
601-499 mg	24	83.33%	8.33%	8.33%	0.00%
1500+mg	20	75.00%	20.00%	0.00%	5.00%

Figures 7a through 7c shows results by type of thiamine. (Note: the original survey did not include a category for allithiamine or TTFD. Many respondents however volunteered they are taking these types.)

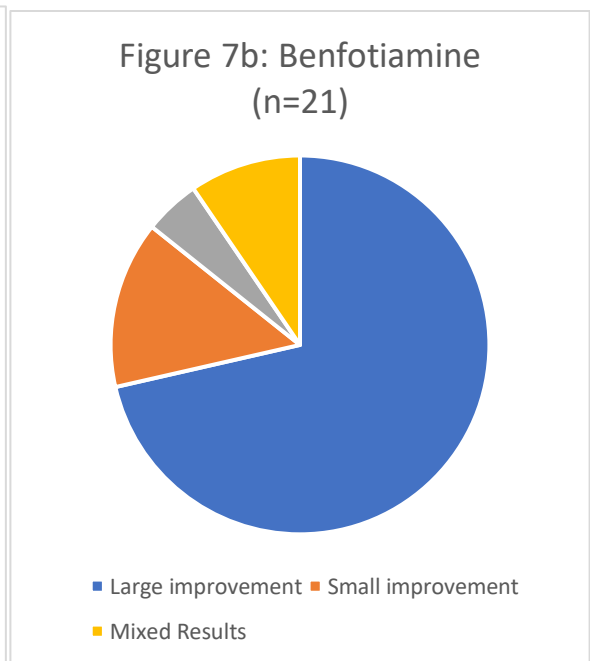
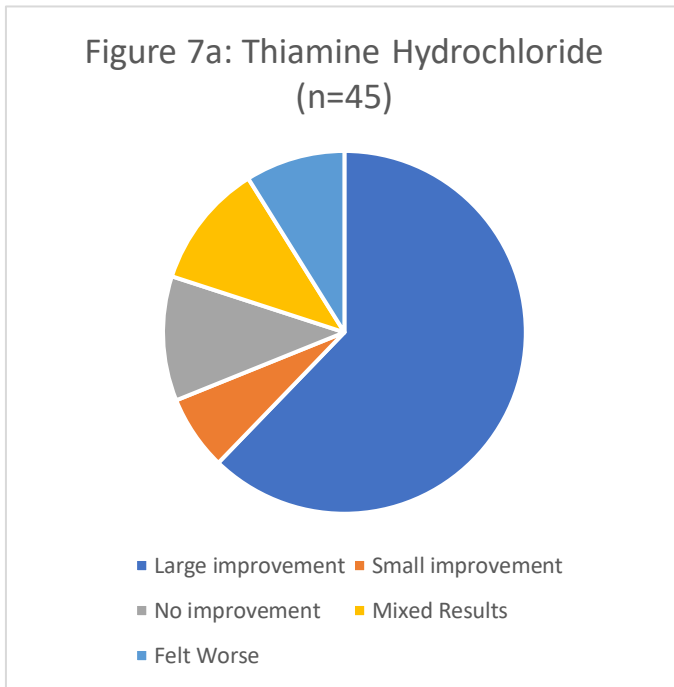


Figure 7c: Thiamine  
Mononitrate+Generic Thiamine (n=24)

