SMCI Answers Reader Questions

SMCI addresses common questions we receive from those in the ME/CFS community.

Q: I was looking for specific information on prevalence of ME/CFS, but I could not find it anywhere. I have heard it said that ME/CFS is more prevalent than AIDS and MS. I was unable to find any prevalence figures today anywhere on the Internet, despite about half an hour of looking. Can you please direct me to prevalence figures for ME/CFS compared to other diseases?

A: According to the Institute of Medicine report published in 2015, “between 836,000 and 2.5 million Americans suffer from ME/CFS” or between 0.3% – 0.8% of the US population. But, as the report clarifies, the estimate varies because different prevalence studies utilize different definitions of ME/CFS and because between 84%–91% of patients are undiagnosed. By way of comparison, multiple sclerosis (MS) is estimated to afflict 400,000 Americans and 1.1 million Americans are estimated to have HIV/AIDS. ME/CFS also afflicts more patients than Parkinson’s (about 1 million Americans), amyotrophic lateral sclerosis or ALS (about 30,000 Americans), and breast cancer (about 250,000 cases a year).

The most recent Canadian prevalence study was released in March 2017 by Statistics Canada and found that 560,000 Canadians (1.6% of the Canadian population) report being diagnosed with ME/CFS by a doctor, a 37% increase from previous estimates. If that same percentage were applied to the US population, it would mean that about 5.2 million Americans have the disease.

It has been nearly a decade since the last CDC prevalence study in the United States so new research using an appropriate criteria is desperately needed to determine an accurate prevalence rate in the United States. Currently, the CDC has no plans to do an ME/CFS prevalence study, despite our many inquiries regarding this issue.

Q: Today was Severe ME/CFS day but no one in my town is aware of that. Where are you putting the word out? I’ve been sick for 45 years. I know social media is considered the best way to capture an audience. But, what about TV? What about using some PSAs? Companies continue their TV advertising, they must be hitting a huge target audience. So, why not try this avenue of outreach?

A: The simple answer is that it is very, very expensive to do this kind of outreach, particularly on television. Neither our organization, nor any other in the ME/CFS space, has anywhere near the financial resources to mount a meaningful campaign.

And at the same time, we make many efforts to get into ME/CFS into the spotlight. When we find low-cost, high-reward media opportunities, we jump on them. Last year, with the support a dedicated and generous donor, we were able to purchase a Times Square billboard advertisement for 3 months reaching an estimated 185 million viewers with information about ME/CFS. In the next Chronicle issue, we will share the details of our work on a two-part series on ME/CFS with a nationally syndicated TV show on PBS. Additionally, we are proud to have instigated a feature story regarding ME/CFS that will publish in the December issues of Ms. Magazine, reaching 110,000 paid print subscribers, in addition to online readers.

So while television advertising is prohibitively expensive for an organization our size, we believe that our donors’ precious dollars are best invested in research and scientific discovery.

CHRONICLE READER SURVEY

Thank you to everyone who completed the reader survey in the spring 2017 issue of our Chronicle, to help us improve The Chronicle and our other publications. We think about the accessibility of our communications and publications.

Font # 3 received the most votes and we will utilize it in our future publications.