

MESSAGE FROM CEO - JULY 26, 2011

Written by Administrator

Tuesday, 26 July 2011 00:00 - Last Updated Tuesday, 26 July 2011 21:02

MESSAGE FROM THE CEO OF THE NATIONAL ME/FM ACTION NETWORK

ANNOUNCEMENTS

July 26, 2011

1. International ME Definition – Carruthers et al

We are receiving many calls and requests as to whether or not the National ME/FM Action Network was involved in the new International ME Definition and I wish to advise that neither myself, or the National ME/FM Action Network had any role in this new definition nor were we asked to participate.

We have not as yet had a chance to go over the definition in detail and are therefore unable to comment on it. We are in the final phase for the September 2011 conference for which the National ME/FM Action Network is host and much of our time is spent on this most important event.

At this moment, the only aspect I can comment on is that I feel personally that it is premature to separate ME from CFS. There are many learned medical practitioners who are properly

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diagnosing ME/CFS as well as there being much research under that label and separating the two at this time will cause much harm to those ill just when awareness and research has increased. Concerns also come into play as to what it can do to the disability pensions which come into question due to creating doubt and confusion when science is still out on the proper name and criteria.

2. Vivint Contest

I would ask you to be patient regarding the problems with Canadian Tax Receipts and the donation issues which we and Vivint are aware of and working on solving the problems which have arisen. Please rest assured that one way or the other you will get a tax receipt you can use and the confusion should be at a conclusion very shortly.

Again I must stress that the National ME/FM Action Network appreciates you voting for us but will not take any aggressive stand on this issue. This contest is doing what other methods have been unable to do, we are getting the best advertising exposure and bringing awareness to those who are not normally exposed to ME/CFS or disability in any way. For that reason alone, the Vivint contest has been a success.

Winning the contest of course would be very useful but it must never be at the expense of others who may have a different viewpoint or loyalty. Go with what you believe is the right thing to do but remember that a vote to a charity who has no chance of winning is a vote lost that could have been used to help another whose goals are as important as the one you are presently voting.

Sincerely,

NATIONAL ME/FM ACTION NETWORK

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Lydia

Lydia E. Neilson, MSM

Founder & Chief Executive Officer.