

RE: UK Based PACE Trial, The Lancet

Written by Administrator

Tuesday, 01 March 2011 00:00 - Last Updated Sunday, 20 March 2011 12:13

RE: UK Based PACE Trial, The Lancet February 18, 2011

Friday, February 25, 2011

MESSAGE FROM LYDIA

STAY FOCUSED

My Dearest Friends:

The natural response to unfairness is to lash out in outrage. Right now is such a time that after some highs some lows have come our way. For those of us who have been around a long time, we are very familiar with those downs as in the past there were many. This is one of those times and it means it takes more effort to stay on track.

There have been many reports over the past 20 years or so of possible causes of ME/CFS and FM, many treatments suggested, and we have been hailed as the laziest people around. You know the old saying, sticks and stones may hurt the bones but words will never hurt me. The negative reports may not be words in the normal sense but they are still the opinions of people which means other opinions and tests can be done.

Now, more than any other time, is the need to stay focused and not react. Remember what we want, a standardized international definition for ME/CFS that not only clinicians but researchers would use so that the test results will be based on the right definition and be more meaningful.

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As long as a researcher can select which definition to use, he or she will use one which suits his or her purpose or outcome. The PACE Trial is a good example.

Another focus which is just as important is that proper research gets done and that we are all on the same page. Researchers need to know what everyone is working on so that there can be better collaboration and quicker results and no repetition.

Our best defense is offence. Get the scientific facts and let them speak for themselves. No amount of outcry will do as much as research results.

Remember we have come a long way from having no information but what that also means is that some of it will be negative. We can choose to concentrate on the negative or stay focused and remember what we are trying to accomplish.

Lydia