



Invest in ME Research

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Charity number 1153730

Centre for Guidelines
National Institute for Health and Care Excellence

NICE GUIDELINES FOR MYALGIC ENCEPHALOMYELITIS (ME)

25 May 2018

Dear NICE,

UK charity Invest in ME Research are stakeholders in the NICE guidelines for Myalgic Encephalomyelitis (ME) and has been submitting comment to all NICE guideline review processes for ME.

The charity did not receive the documents for the workshop of 25th May 2018 until the evening of Tuesday this week, despite having already registered our intention to attend and other stakeholders seemingly having received these documents earlier.

Why we have not received them is an interesting question.
We hope you will correct this oversight in future.

As the charity is very busy preparing for the International ME Conference Week events in London next week then this lamentable lack of warning has meant that we do not have time to attend or prepare adequately for your workshop.

However, we would like to submit these brief comments for input to discussions.

As we have communicated to Professor Mark Baker previously [1] we find it totally illogical and negligent for NICE to continue to maintain existing guidelines for ME that recommend CBT and GET.

We have provided evidence and reasons why both CBT and GET must be abandoned – NOW!

The fact that NICE has ignored this request means that NICE must be accountable for any harm coming to people with ME due to the consequences of CBT and GET as recommended by existing guidelines.

It is still not too late to act.

As we have stated this decision can and should be made irrespective of any review. Both CBT and GET must be removed.

In the short time that we have had available for your workshop then we must make these comments.



The Lightning Process

- Why is NICE mentioning this in the scoping document?
- If this is due to the SMILE study published by Crawley et al then it seems as though the group has not looked at the study and its serious flaws or evaluated the trademark business the Lightning Process itself – which we view as a pyramid business that has no regulation, no accountability and no science behind it
- How can a technique that tells participants to be secretive about what it entails be taken seriously or included in NICE review?
- Of course, NICE must remove LP in any discussion regarding guidelines for ME

CBT and GET need to be removed now

- CBT (the supportive type) can be offered in any case to patients as required
- CBT does not need to be mentioned as a main type of treatment
- CBT (directive) needs to be discarded altogether
- GET has no evidence of being beneficial and may be harmful

We ask that you consider these points.

No doubt after the conference week events – which sees researchers and delegates from twenty countries attending our events and presenting, discussing and collaborating on biomedical research, something the charity has been doing for **13** years – there will be more time to prepare for NICE guidelines processes. We hope that NICE will ensure that Invest in ME Research is no longer excluded from receiving information beforehand,

Yours sincerely,

The Chairman and Board of Invest in ME Research

References

- 1 <http://www.investinme.org/IIMER-Newslet-1801-01.shtml#IIMER-reply18-2>