



# **Invest in ME Research**

## **Statement September 2017**

Charity number 1153730

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### **The SMILE Trial and Its Not-So-Happy Aftermath**

21 September 2017

Invest in ME Research has never approved of the Lightning Process (LP) business and its model of operation where former 'recovered' patients pay a lot of money to become practitioners of this Trade Mark training programme.

We view this as a pyramid business – unregulated, unaccountable and unscientific. Claims that it cures people with ME we find as risible hype.

Since 2010, we have made objections about the SMILE Trial [1] – an abhorrence in this age when we should be investing in biomedical research into ME in order to find causes for this disease.

Instead, funding is allocated to a commercial business enterprise to test it out on children.

It is shameful that any self-respecting researcher would participate in this.

It is disgraceful that any media outlet with any integrity would just take the press release of a media centre which is known for promoting a false view of ME and then avoid doing even the most basic of journalistic tasks – such as research of the information.

It is especially disgusting to witness the hypocrisy of some organisations who now complain about training programme - yet all the while seem to be happy to sit in the same **"big tent"** along with the SMILE Trial PI, in a so-called collaborative organisation which continues to support this sea of research dross.

What a sickening spectacle!

Any ME charity or researcher promoting this training programme, or working with the people that carry out this research, is doing a great disservice to ME patients.



On the day after what would have been the 40<sup>th</sup> birthday of a young woman, whose life was taken far too early by this disease, instead of remembering her ordeal we are, instead, treated to another media blitz from biased editors covering more junk research.

The lemming-like media in the UK perform their usual subservient role and unhesitatingly follow the propaganda issued by the Science Media Centre (SMC) and continue their usual discrimination against people with ME and their families.

Not for the UK media any rational analysis of why people with ME are frustrated for a generation by mindless junk research or by disingenuous spokespeople claiming to represent them.

Instead the media trot out the same lies about death-threats against researchers (normally only two) - yet ignore the plain fact that patient-funded research is thriving with researchers clearly enthused about the possibilities of finding the real cause(s) of this disease.

What the media should really look at is the IIMEC11 pre-conference dinner presentation by Kjersti Krisner [2].

This clearly shows what harm ignorance about ME can be done when vested interests manipulate and distort the true nature of this disease.



Then the media should follow up by viewing David Tuller's IIMEC12 pre-conference dinner presentation [3].

Two presentations clearly showing the failings of establishment organisations and their supporters – and the misery dished out to people with ME.

Effect and Cause.

While Dr Esther Crawley - the SMILE PI – has been congratulated by the chair of the CFS/M.E. Research Collaborative (cmrc) for her stunning and amazing work;

while the chair of the cmrc may be “thrilled” that four years down the line from its inception his organisation merely has a room full of people at its meeting to show for that period – and is unable to avoid the realisation that this organisation has achieved nothing of significance;

while some are sitting happily in the establishment **big tent** alongside the SMILE Trial PI and do not see anything incongruous in that situation;

while some who never objected to the trial in the first place now seem to want to appear concerned ;

while the establishment media centre pumps out more spin about ME,

while lazy journalists do no research on the subject and continue to act as puppets of biased media editors ;

while this entire circus continues people are suffering from this disease.

All of these years have gone past – and nothing has fundamentally changed regarding establishment policies towards research into ME it seems.

And the lives of patients roll by – with many who influence research policies for ME, and their supporters, seemingly oblivious to the waste of life, of opportunity, of any sense of really making a difference to families affected by this crippling disease.



The LP business has no place in serious research and cannot be researched seriously, as it tells people to keep its methods secret, to deny they have ME.

This alone should be a big red flag to anyone.

How funding could have been given to this in the first place ought to be a subject for the media to research.

These quick and dirty solutions to a society increasingly founded on soundbite healthcare will leave a trail of sick patients and despairing carers, and a tragic dystopia.

And everyone, save for perhaps the business practitioners, will be the poorer for it.

- 1 <http://www.investinme.org/Article-501%20Childrens%20Study.shtml>
- 2 <https://youtu.be/SHUnC3ZoMKY>
- 3 <http://www.investinme.eu/IIMEC12.shtml#dvd>
- 4 <http://adc.bmj.com/content/early/2017/09/21/archdischild-2017-313375>  
Crawley EM, Gaunt DM, Garfield K, et al  
Clinical and cost-effectiveness of the Lightning Process in addition to specialist medical care for paediatric chronic fatigue syndrome: randomised controlled trial  
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