

mechanism, involving a Russell Group University, a very large paediatric CFS centre with outposts around the country and a children's charity – with support from the Science Media Centre, and even the CFS/ME Research Collaborative!

The influence of this powerful alliance is sweeping all who stand in its way into oblivion – not only severely ill ME children and their families, but also the only UK consultant specialist in severe paediatric ME who had the courage to be effective in supporting and protecting them. He has now been silenced via the General Medical Council : is not permitted to see patients, speak at conferences or continue his role with international teams of paediatric ME/CFS specialists. As the mother of a chronically ill daughter, I find the outlook terrifying.

Natalie Boulton

You can read this presentation in full at

<http://voicesfromtheshadowsfilm.co.uk/2016/presentation-for-belfast-6th-june-2016/>

Natalie was speaking at the *Chasing Competent Care* Conference in Belfast on 6th June 2016.

Many congratulations to Natalie for her excellent presentation and to the organisers - Hope 4 ME & Fibro NI (Newry & Mourne Support Group) - for hosting such a great conference.

The conference featured several other speakers, including Prof Malcolm Hooper with a review of the 'PACE' Trial (see below).

The conference delivered a strong message calling for change to the currently inadequate care situation for ME and fibromyalgia patients in Northern Ireland, and featured a display of shoes as part of the #MillionsMissing campaign.

You can read more at:

<http://www.meaction.net/2016/06/20/n-ireland-chasing-competent-care-and-millionsmissing-protest/>

'Millions Missing'

'Millions Missing' is a fabulous awareness raising initiative from #MEAction (www.meaction.net).



We love the idea of the shoe display which forms the back-

bone of the campaign. Campaign supporters are asked to contribute pairs of shoes. Each pair carries a tag with the name of a patient unable to participate in their once-active lives. In the case of Belfast, over 200 pairs of shoes were displayed down the side of the conference hall, lined up to the speaker's podium. This must have had a very powerful visual impact!

Also many attendees read the comments on the tags that described the devastation caused.

Well done!

The 'Millions Missing' campaign hit home in 13 cities across the world. The picture here is from London event.

'Sea of empty shoes left outside Department of Health in global ME protest' was the accompanying headline in the London Evening Standard, which advised:

Activists remained completely silent, some wearing gags over their mouths, as they protested alongside the pairs of shoes from midday to 2pm.

Tom Marshall, Wed 25 May 2016 (Photo by Robert Tanzcos)

Round 2 is planned for September 27th.

For updates visit:
millionsmissing.meaction.net/

Prof Hooper on 'PACE'

Speaking at the Belfast Conference on 6th June, Prof Malcolm Hooper queried the promotion of results that carry such marginal benefits and such great potential risks.

If asked to undertake these 'therapies', Prof Hooper recommended that patients reference:

The PACE Trial Invalidates the Use of Cognitive Behavioral and Graded Exercise Therapy in Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: A Review by Mark Vink

Journal of Neurology & Neurobiology 2(3): doi <http://dx.doi.org/10.16966/2379-7150.124> Pub 30 March 2016

The paper can be read here: www.sciforschenonline.org/journals/neurology/JNNB-2-124.php

25% ME Group membership statistics

When a person joins the 25% ME Group we ask if they have tried graded exercise and cognitive behavioural therapy, and if so with what effect. These are the statistics for 234 members who had tried GE and 191 who had tried CBT:

Were you made worse by GE? Were you made worse by CBT?

Yes 203 = 86%

Yes 79 = 41%

No 10 = 4%

No 29 = 15%

No Change 25 = 12%

No Change 83 = 43%