



Association of Young People with M.E.
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Dear Ethics Committee Members

I should like to thank you for allowing me the opportunity to attend the hearing today and to give my sincere apologies for being too ill to attend. I can't begin to tell you how disappointed I am as it would mean so much to be able to explain in person how I and my Board of Trustees feel about the events leading up to today. I am able to speak on the telephone should you wish to call and put me on speaker phone and am contactable on *****.

I have known Dr Crawley now for eight years and The Association of Young People with ME (AYME pronounced aim) is both proud and privileged to have her as our Medical Advisor. In all of the time I have known her and observed her in her dealings with children, young people and their parents and families she has been a consummate professional always aware of and sensitive to their individual needs and this leads me to passionately believe that she would never undertake any activity which might lead to even one of them being harmed through any activity or research she is involved in. Their best interests always come first. An example of this is, she is the only paediatrician who is prepared to travel the length and breadth of the country, often in her own time, to help those children who are bedbound and most severely affected with M.E.

The Lightning Process has caused controversy since day one amongst a very loud and active minority of adult M.E. patients who are against any kind of psychological or psychiatric support for M.E. patients. AYME currently has over 3,000 members and we regularly receive letters from children and young people who have been significantly helped by this training programme. How and why is the question which urgently needs addressing, as when parents call the helpline at the moment all we can do is point them in the direction of the LP website and tell them to read the information carefully before making their decision. They know people have been helped to varying degrees having read letters in our magazine. AYME has not had any letters or received any calls from parents whose children have been damaged by participating in the training but we of course have been made aware, via third parties, of some children who are said to have relapsed and been made worse. I cannot comment on these as I don't have any facts and certainly none of these have been brought directly to AYME's attention.

Cheerful support for all children and young people with Myalgic Encephalopathy

Reg. Charity No: 1082059 President: Esther Rantzen OBE
Associate Member of the Telephone Helplines Association

AYME Ltd, Co Reg No 03981646
R/O Sunbow House, 5 Medland, Woughton Park, Milton Keynes, MK6 3BH

I believe, as do my trustees, that it is essential for this research to proceed if 250 children a year are reportedly participating. We must have the information needed to make informed decisions about its efficacy, and the first question has to be can enough people be recruited to make this feasible. We need to eventually understand how it is helping these patients so that once we really understand it aspects of the training can be absorbed or not into the NHS services.

What I do know is that Dr Crawley would never put a single child at risk in order to achieve the aims of the research; their needs would always come first. To even suggest otherwise is unprofessional and offensive. Why not use adults first? We are repeatedly told and hear that children respond differently to therapies and treatments and know that their recovery rates if they receive the right treatment are far better than for adults so to me it feels as though this is the right place to start.

As I said at the beginning I am more than happy to speak further about this and hope this can be quickly resolved to allow the study to proceed.

Yours faithfully

Mary-Jane Willows
CEO AYME

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