

## Press Report on Trust's visit to Carlisle

Former Head Teacher Jane Colby, Executive Director of the The Young ME Sufferers Trust (Tymes Trust), talked to Carlisle ME/CFS support group about her recent presentation to the All Party Parliamentary Group on ME. The Trust has helped thousands of families over the years and in 2010 received the Queen's Award for Voluntary Service: the MBE for volunteer groups.

### There are in Jane's view 3 misperceptions that affect patient care:

1. That ME is a mental health disorder
2. That treatments recommended by the National Institute for Clinical Evidence (NICE), can always be expected to 'cure' or substantially improve the condition
3. That the illness is neither long lasting (chronic) or severe.

Tragic consequences of such mistaken views include parents unjustly suspected of harming or neglecting their children, the denial of suitable education, and incarceration of children in psychiatric wards when treatments fail to work as expected.

The Trust, Jane explained, is a practical charity that addresses such injustices in its case work, campaigning and research. The Trust has co-funded an exciting study at Dundee University which showed that ME is a physical illness. Researchers found an abnormal level of inflammatory chemicals in children's blood and an abnormal rate of white blood cells dying. Professor Jill Belch said this was consistent with a reactivating or persistent viral infection. The children's quality of life was significantly worse than children suffering with other illnesses (type 1 diabetes mellitis and asthma).

The study also found that only one child out of 25 was able to attend school full time. This confirms the Trust's experience that access to education is badly impaired. Children have a legal right to suitable education. This does not mean having to attend school – schools must provide other means of education if the child is too ill to attend. Virtual education or home tutors are suitable alternatives.

- In the last two years alone, the Trust has assisted more than 70 families subject to child protection investigation, whose children have ME.
- All 100% of these investigations were found to be without foundation. No figures are kept on such cases by government; it is not known how many more there may be.

Jane also explained that the Trust works with American virologist Dr John Chia, who is about to announce a new breakthrough. The Trust has funded tissue samples from some of its young members to be analysed for enteroviruses and all were positive. Enteroviruses are related to poliomyelitis. They infect the gut and can persist years after the original infection. There is a specific protocol that must be used for the test.

The Trust hopes that its work will help lead to a diagnostic test and that curative pharmaceutical treatments will be developed. In the meantime, Jane says: 'Doctors need to make sure that a mild case doesn't turn into a severe one through inappropriate treatment. We regularly work with our members' GPs to help and advise.'

by Linda Daniels and Jane Colby



## GP project praised by uk government

Building links with your GP

Earlier in 2011, our Founder Patron, Lord Clement-Jones, received a letter from Health Secretary Andrew Lansley about our GP Project. This project is our newest member service. Mr Lansley writes: 'I was encouraged to learn of The Young ME Sufferers Trust's work in building links with the GPs of those children suffering from CFS/ME. The lack of certainty surrounding CFS/ME poses very real problems for healthcare professionals...'

The Trust has always believed that an understanding GP is invaluable in helping the family cope with ME. If you would like to discuss how our personalised GP Project could help you, call the Trust's Advice Line Team on 0845 003 9002.

Register for Jane's monthly email News Alerts by letting us have your email address. (If the Alerts don't come into your Inbox, check your spam/junk mail box.)

You can follow Jane on Twitter @JaneCColby or read her latest tweets at [www.tymestrust.org](http://www.tymestrust.org) A facility that's personal, informative - and fun.



The Queen's Award  
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