



Good news! The Young ME Sufferers Trust's website has been recommended in the *International Consensus Primer for Medical Practitioners on Myalgic Encephalomyelitis (ME)*.

The authors state: 'Tymes Trust: most comprehensive information regarding education of young people with ME <http://www.tymestrust.org>'. The Primer also has its own version of our Tymes Trustcard, a real compliment to our work!

The International Consensus Panel consists of 26 medical experts led by Professor BM Carruthers, who believe, like us, that medicine should formally separate the discrete neurological disease 'ME' from the nebulous 'CFS' under which so many patients are being caught. People with ME can be damaged by unsuitable treatment. People with other conditions need to be properly diagnosed, rather than being told they are 'chronically fatigued'. They know that already! They need to know why, and to receive the right treatment for them. There are worrying instances of patients labelled as 'CFS' eventually being rediagnosed with

other conditions. They should have been properly diagnosed earlier. Mixing different pathologies also confounds research studies.

The Primer is based on the Panel's *Myalgic Encephalomyelitis International Consensus Criteria*, which states: 'Using "fatigue" as a name of a disease [...] has been the most confusing and misused criterion'. They also explain: 'In view of more recent research and clinical experience that strongly point to widespread inflammation and multisystemic neuropathology, it is more appropriate and correct to use the term "myalgic encephalomyelitis" (ME) because it indicates an underlying pathophysiology. It is also consistent with the neurological classification of ME in the World Health Organization's International Classification of Diseases (ICD G93.3)'.

We will of course do our best to help, whichever of these diagnoses you have been given. Change takes time.

Kindest regards,  
**Keith Harley Chair of Trustees**

## Scottish Parliament

### Cross Party Group on ME



The Convenor of the Scottish CPG on ME recently forced a vote to change the name and remit of the Group to include CFS and other fatiguing conditions, saying she would resign and the Group would be closed if the vote was lost. A 'Centre of Excellence' was mooted along the lines of the fatigue clinics south of the border.

This all seemed undemocratic, and a retrograde step when international experts are now defining ME as a separate disease to avoid people being treated for poorly defined 'chronic fatigue'. CFS has been a disaster; treatable conditions are missed, children relapse after being pressurised into school while still ill, and adults made worse by inappropriate therapies. Many of us therefore voted against by 30 to 5 (12 abstentions) and a complaint was sent to the Scottish Parliamentary Standards Committee. The Convenor resigned and Scotland now has no Cross Party Group.

This was a wholly unnecessary confrontation, but patients are now standing up for themselves. This is not just a matter of the name of the illness, but of people being accurately diagnosed and appropriately treated. And of children being protected from establishment dogma.

### Lesley Scott, Tymes Trust Representative Scotland

*Lesley is working to improve care and education for children north of the border.*

### @JaneCColby

### November Tweets

'Just read final draft of new govt guidance on ed for sick children. If it survives the next phase in that form, my recommendations are in.'

'Thurs 29 Nov is Young Hearts Day. We're marking this year with an Ask Tymes Trust session. Starts 4pm. Tweet me yr questions and add #AskTT.'

*No need to join Twitter to follow Jane's daily tweets. Go to [www.tymestrust.org](http://www.tymestrust.org) and click on the link to view.*

### Did You Know?

Some fundraising websites charge charities to register with them, but our Trustees have vowed not to give families' hard earned money away like that. So we're listed with EVERYCLICK, where you can set up a Donations Page, like Steve, and collect sponsorship online. They also send us the Gift Aid. See <http://www.everyclick.com>



## Thanking Our Intrepid Fundraisers

It's Tyme to publicise your efforts. Here are some of your enthusiastic activities. We hope you had fun! We can make the smallest donation go far, as our work is pro bono and no-one at the Trust is paid for their time. Thank you all so much.

## Climbing Helvellyn



Steve Moxon and the guys successfully climbed Helvellyn on a misty October day, raising a magnificent £2,000. With Gift Aid and a £1000 donation from Experian, the total is almost £3,500. Steve says: 'After the support we have received from Tymes Trust we are so happy that we can show our gratitude in such a practical way.' He adds: 'I think some were happy for the mist on the way up as they couldn't see how far the drop was!'

## Pyjama Day



Alice Gregory with Callum Buckingham on Wear Your Pyjamas Day at Westgate Nursery School and Creche. Both have ME. Alice's mum is the Nursery Manager and Callum is an apprentice studying towards an NVQ3. The Nursery raised £126. Congratulations!

## Concert



Irene Leet and Gill Tincknell organised and performed in a concert at Parish church, Midsomer Norton, Somerset, raising the magnificent sum of £2,030 for the Trust's work. Penny Root from our Advice Line addressed the audience, describing her family's own struggle with ME. Penny comments: 'The mayor and his wife sat in the first pew, just in front of me, alongside the local MP. It felt very warm and "neighbourly" in that church, but I didn't guess quite how much so!' Penny is willing to give her moving talk in other areas around Bath.

## Russell's Tour

I've just returned from a summer abroad, I never thought I'd be able to leave my bed let alone the country!

## Our Latest Young Officer



If it wasn't for the help and support we get from you and everyone who help runs Tymes Trust, I really wouldn't be as good as I am now. I'm now getting outside most days, and I've been able to go shopping in our local high street once a fortnight! I cant believe some professionals just don't understand how important it is to listen to my body and to sleep loads!

**Hannah Barnes,**  
**Tymes Trust Young Correspondent**



The sunset in Ibiza, one of the best in the world! :)

## Thanks To

## All Fundraisers



Tymes Trust Young Officer Jen Flynn and her friends have raised £1,581.00. Many thanks to her and all of you who loyally support the work of the Trust. Please let us know if we can feature your name.

## Young Hearts

## Awards 2012



I thought I would share the excellent support we have had at my daughter's secondary school. The SENCO and all teaching staff have been really supportive [...] There is no pressure to increase hours. There seems to be an understanding that education can be undertaken over a lifetime not just between age 5-16, so when she is able, she can catch up. I realise that we have been very lucky. Thanks again for the information in your e-mail updates.

**Sue Davis**

**Young Hearts Certificates go to:**

**Parklands High School;**  
**Mr Betney, teacher;**  
**Dr Boyes, GP.**



## From Jane's

### Inbox

I managed to keep my son from getting permanently worse by fighting like a lion mom with school personnel, in several schools, over three continents, with YOUR PUBLICATIONS in my hands. It was the main reason why I left Switzerland again after a six month trial period there. I was one of the parents living with fear from child protective services! I am glad I was able to protect him and he is health wise better than many children with ME. I am glad that your publications made it into the new Primer for Medical Practitioners. **(Identity protected)**



We ran out of space! Sorry if we couldn't fit you in; send us your news for next time.

## Shannen

### Dabson's Rabbit

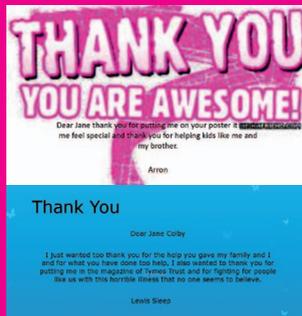


Tymes Trust Young Officer Shannen Dabson's rabbit wanted to borrow our poster on sleep! Poster reads: 'Please don't wake me up'. We support daytime naps.

## Arron And

### Lewis Sleep

Arron and Lewis Sleep designed Thank You messages to Jane in Powerpoint!



## Tasha

### Mawer's Photos



Tasha Mawer's got a new camera and is busy taking pictures when she can. She is hoping to study photography.

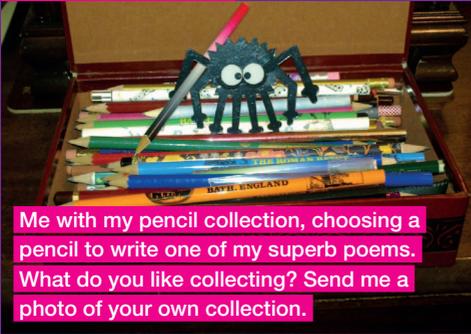
## From our Inbox



Bella Hoare writes: 'My website for the sufferers of ME/CFS is mainly aimed at children and teenagers, but anyone with ME is welcome to register! Come to [www.mespace.org](http://www.mespace.org) and contribute some artwork!'



## Seb's Spread



Me with my pencil collection, choosing a pencil to write one of my superb poems. What do you like collecting? Send me a photo of your own collection.

As the most artistic spider on the planet (and the most modest) I have the honour of announcing our Young Hearts poetry winner. And the winner of the Young Hearts ecobag is – Paige Ann Golding for her poem *Mummy and M.E.* It's hard to get any better if you're trying to do all the things mums do. Reading it aloud made me cry. I didn't know which legs to wipe my eyes with!

We've loved reading all your poetry: MORE PLEASE! All our poets get a Special Letter and we'll publish as many poems as we can. We've chosen a 26+ winner as well. Naomi Whittingham.



Please give me a home

## Mummy and M.E.



Paige (Age 14)

My Mummy has M.E.,  
I can't understand it you see.  
She can't walk very far,  
Not even drive a car,  
I really can't explain,  
I know her workload is to blame,  
But it's such a shame.

My Mummy can't cook our tea,  
But tries her best to look after me.  
She is too ill to work you see,  
It has affected us all financially.

My Mummy doesn't eat very much,  
And can't really manage to keep in touch,  
Friends they now get few and few.  
Not understanding, if only they knew.

I wrote this poem for you to see,  
how this virus has affected my Mummy.

## Mr Harley's

## Snowy Winter Bears

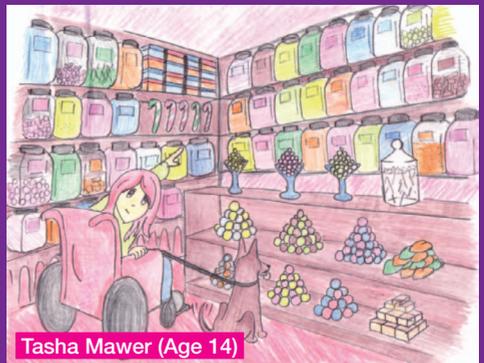
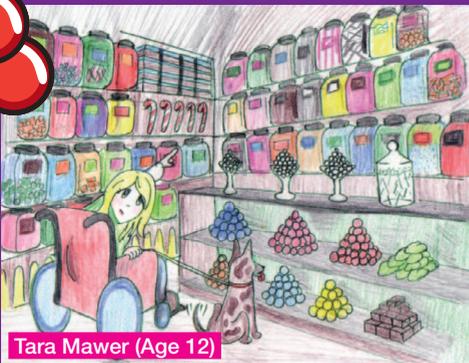
Mr Harley has found more bears! So he can once again offer his Annual Gift of Bears! Let us know quickly if you'd like one as a Special Present. This bear is lonely (aaaaahh).



## My Art Gallery

Our prizewinners! Gregory, Anita and I are totally impressed with all your colourings of his Sweetshop. It must have

taken ages. All those different coloured sweets... um yum! Turn over and you'll find Gregory's Christmas to colour.





### Colour Gregory's Christmas!

Send your colouring to us for a prize. Include a stamp if you'd like it returned, and don't forget to add your name and address!

Send to: Gregory's Christmas, Tymes Trust,  
PO Box 4347, Stock, Essex, CM4 9TE.



Name, Address & Age

### Prizes for the severely ill

Gregory and Anita say: 'If you're too ill to colour, imagine what's in these parcels and stockings. Get mum or dad to write or email us with your ideas'. The Contact Us form is at [www.tymestrust.org](http://www.tymestrust.org)

**The Young ME Sufferers Trust**