mini Vision

WITNESS STATEMENT PUBLISHED

ME CENSUS BACKED BY MEDICS

EMAIL ALERTS SUCCESS

I In ME Awareness Month I have, as always, got exciting news for you but first let me say how pleased I am with the success of our Email Alerts. This is the sixth time that you've heard from the Trust in 2009 - the internet is a great tool for news. If you aren't on the Alerts system, let us have your email address. You can read previous Alerts too; Mark Colby has uploaded them to our website.

This ME Awareness Day, the Trust launches a call for an ME Census. We are calling on GPs' surgeries to use their software facilities to obtain statistics on how many cases of CFS/ME/PVFS are on their books. We are backed by Consultant Neurologist Abhijit Chaudhuri, who said: 'Any way we can get figures about this illness is good news.' Dr Nigel Hunt, GP and Associate Director of Postgraduate GP Education, Eastern Deanery, has also praised this practical idea. You will hear more about it in the coming months.

The Trustees are also publishing Jane Colby's Witness Statement, written at the request of the patients who brought NICE to Judicial Review. The Judge quoted Jane's Statement in his Judgement, which makes it a public document. Of course, not everything in the NICE Guideline is bad, but we feel that the core recommendations are potentially damaging to people with classic ME. As Terry Waite, one of the Trust's patrons, said recently: 'It doesn't mean that if you oppose what someone is doing that you're necessarily against them in totality.'

I hope that some of you can come and meet us at the RSM conference which the Trust has helped to organise.

Kindest regards,

Keith Harley
Chair of Trustees

Outside the Royal Courts of Justice for the Judicial Review

Things 4 U 2 Do

SUSIE'S MAGIC RIVER

We've put a full-size copy of this picture by the Trust's resident artist Susie Jayasinghe on our website for you to download, print and colour.

1 Go to www.tymestrust.org
2 Click on Tymes Magazine
3 Click on Susie's picture
4 Print off and colour
5 For a prize, send it to us; we'll also print it in the next full-size Vision if we have room.

Shirley Conran Writing Awards

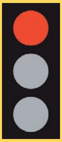
Write us a story or poem about the river and win one of our Shirley Conran Writing Awards. You can read a previous story by Katharine Perry in Vision 2008-2. If you don't have a printed copy, find it on the same web page.

THE POLITICS SHOW

In the run-up to ME Awareness Month the Trust has been working on an awareness-raising feature with the BBC1 Politics Show and Samantha Brown, a student with ME.

It was a great day for Samantha at the Houses of Parliament. First, she was brought to an All Party meeting with Jane Colby, then reporter Max Cotton interviewed them on the Victoria Embankment in dazzling sunshine against the backdrop of the House of Lords, where our Founder Patron, Lord Clement-Jones, has hosted a number of Trust events.

Max asked Jane why someone who looked well should be entitled to benefits. She said: 'Suppose Samantha had asthma or epilepsy? Could you tell that from looking at her?' Jane explained that after someone with ME has made a big effort, there is typically a delayed downturn afterwards. But people only see them in public when they're well enough to go out; they don't see the after-effects. Samantha was unfortunately quite ill after her trip to Westminster.



Thou Shalt Not!

They told me everything was banned
I mustn't switch my - - - - - - -
But I like having pencils - - -
A little pad to write on.

My bedroom was a sound-free zone
And mum was banned from staying
So I must lie here all - - - - -
Without my music - - - - - - - .

But as my brain thinks day is night
I'm wide awake at three!
We just don't think they can be - - - - -
Their rules don't work for - - .

So now I play some gentle sound
Til in the end I slumber
And wake with all my things a - - - - -
As cool as a - - - - - - - - !

Don't forget - in each verse, line 1 rhymes with line 3 and line 2 with line 4. Count the dashes, one for each missing letter. You might need a little help...

Sebastian Says

I had a great holiday with the Trust's Young Artist, Chloe Halstead, her sister Amber and their family. Could I visit you perhaps?

I want lots of entries for my Poem Competition. You could win my Westminster Bear! First correct entry wins the bear, and I have lots of new prizes for everyone else - unless I run out! Can anyone can beat Elizabeth Bell, who has won three times now?

*At bedtime I was **most** impressed to find a set of specially tailored PJs waiting. Now that's hospitality!*

Every Click

Jamie Hewitt says:

Here's a great new way to raise money for the Trust. Everyclick is a search engine that gives a donation to charity each time you use it. The Trust now has its very own Everyclick page where you can raise money for the Trust just by clicking your mouse! It's that simple. Five people have already raised more than £67 and with your help it could be a lot more. To start searching and raising money, go to www.everyclick.com/tymestrust.

Jamie's being modest - he designed this page and it's beautiful! Do go and take a look.

what you think

My daughter Jasmin received a letter from Jane Colby about funding from the Nisai Virtual Academy. Her eyes lit up as she thrust the letter into my hand. After scurrying around to get information together we sent off the application.

Within a few days Jasmin received her welcome pack. To say she was over the moon is putting it mildly. She cried with excitement and relief. Relief because she should have sat GCSEs in 2008 but had missed all of Years 9, 10 and 11. Jasmin now really looks forward to each day. This has given her back a future which she thought she had lost forever. She is enjoying her assignments and her work gets marked very quickly and thoroughly. Her mood and attitude towards life has changed dramatically since starting with NVA and thanks to them, the Learning and Skills Council and Tymes Trust my daughter has been given a wonderful chance at life again.

She has always been a bright and clever girl but ME sent her into the depths of darkness where she spent many months paralysed and having to be spoon fed pureed food. Words cannot describe what an amazing life changing thing she has been offered, all for the price of a phone call and a stamp. There is no way that we could afford to pay for this ourselves. She realises what a great opportunity she has been given and is working really hard. She has taken to it like a duck to water. Also, within the last couple of weeks, after 3 years of not being able to walk, she is starting to take her first steps!

We are so thrilled with this opportunity. You can be guaranteed that not a penny of the funding will be wasted. Her lowest assignment mark was 80% and she has now had 2 assignments marked at 100%. Many thanks for all your hard work at the Tymes Trust in everything you do but also for securing funding for the NVA.

Jo and Jasmin Wakeford

You can email us on the contact form at www.tymestrust.org or send a letter.

Parents : could you be a friendly voice on the telephone for two hours a week? Please call 0845 003 9002.

Cover Picture : Order! Order!