

Mini Vision



ROYAL SOCIETY OF MEDICINE

USA COLLEGE TEXTBOOK

WIN OUR GIRAFFE

This spring and summer has seen significant developments for the Trust's work, including resolving yet another mistaken child protection investigation of an innocent family. The mother writes: 'Thanks for literally saving our lives! (Well that's how it feels to us!)' Contact us if this happens to you. Dr Nigel Speight, on our Professionals Referral Panel, works with us on such cases.



We have changed our 2009 *Vision* schedule to allow for other initiatives, including Jane Colby's analysis of questionnaires and writing *The Colby Report*. This updates and extends her first ME book in the 1990s, *ME - The New Plague*, featured on Sky's *Tonight with Adam Boulton* when the Dowsett/Colby study appeared in the *Journal of Chronic Fatigue Syndrome*. New members may not know that it was their study which revealed that 51% of long term sickness absence from school was caused by ME, the largest cause by far. I am delighted that the story of Jane's fight to get the study recognised by the

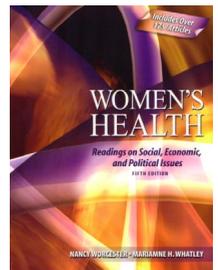
British medical establishment has now been published by the University of Wisconsin - Madison, in an American college textbook in a chapter titled 'Politics of Disease, Prevention, and the Environment'.

I am extremely concerned that we are hearing from parents about adverse reactions to fashionable graded activity programmes. This style of treatment for classic ME was all the rage some years ago but now it's back with a vengeance, since NICE endorsed it. We urgently need to hear from you, in confidence of course, if you have been similarly affected. Write to me personally if you wish.

Kindest regards,

Keith Harley
Chair of Trustees

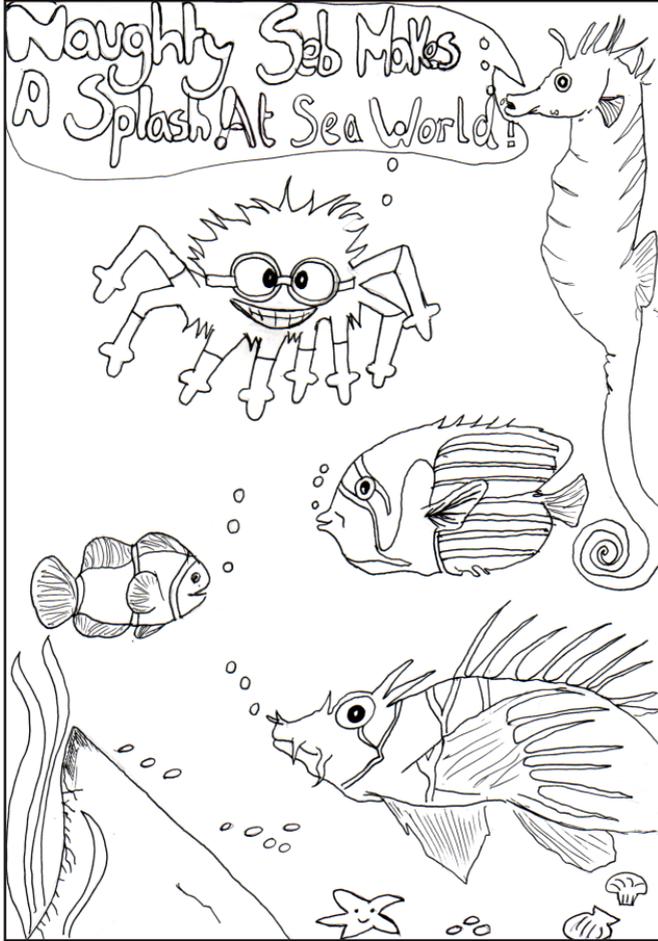
*Women's Health:
Readings on
Social, Economic, and Political Issues
Dept of Gender and Women's Studies
University of Wisconsin - Madison*



Things 4 U 2 Do

CHLOE'S

COOL COLOURING



PARENTS ALERT!

We're told that it gives young people a real boost to get a surprise from the Trust through the post.

You can help with competitions if your child's not well enough to do it on their own. We tailor prizes to age so no-one's too young or too old to join in.



NAME THE GIRAFFE!

Win our Giraffe! Katie Durben, our Friends' Co-ordinator, has made him specially for you.

The Judge, our Chair of Trustees, says he needs lots of names to choose from. Email giraffe@tymestrust.org or write in - we have more cuddlies for the runners up!

Wild Things

Wot me? A giraffe?
You're 'avin' a s-----!

I'm really an ape
of unusual sh-----.

No, that's really not t-----.

I'm a strange cockatoo.

or a bird that can peck
with a very song n-----?

Or a dog that likes w-----?

(I'm telling you porkies!)

I'm cuddly and s-----

and I tower aloft

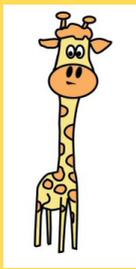
over other soft creatures.

My very best f-----

are humour and laughs

unlike other gir-----!

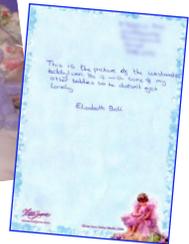
Find the missing rhymes! Each dash is one letter. We've shown you how each word begins. Special prize for the first correct entry - more prizes until we run out! Let us know if you want us to print your name.



Sebastian Says

Elizabeth Bell won the poem competition AGAIN! She's sent in the first correct entry to our poem comp four times running - there's no stopping her. So I decided to make her our 'Competition Champ' and sent her our Westminster Bear. Here he is chairing the inaugural meeting of the All-Cuddly Select Committee on Equal Opportunity Hugging. You

could be a Competition Champ too.



As you know, I'm in charge of the prizes. But I've been very magnanimous and allowed the Chair of Trustees to judge the Giraffe names. I don't know why I'm so generous, I just can't help myself.



Because of her talent and enthusiasm (qualities she shares with me, like modesty) we've appointed Chloe Halstead as our Young Artist. She's drawn a cool picture of me for you all to colour in. I'll print them in Seb's Manor if you send them to me.

S

www.everyclick.com/tymestrust

Everyclick Trust has its very own by clicking is a search engine that donates to charity each time you use it. The Trust has its very own Everyclick page where you can raise money for us just by clicking your mouse!



what you think

From a speech to the Royal Society of Medicine by Tymes Trust Advocate Shannen Dabson (read the whole speech at www.tymestrust.org)

I have had ME for 6 years. I turned so quickly from a lively, popular girl into someone who couldn't walk far, found standing impossible, couldn't abide the smell of food cooking, bright lights or watching TV and I soon needed a wheelchair. I achieved many small goals thanks to it. After the first summer I gave it back. By winter I needed it again. I was heart-broken when it was delivered - and to think I'd been almost excited with relief to see it first time around! I started to get really low and had to be carried everywhere.

Some friends I had to lose as they turned out to be fair-weather friends. The friends I kept surprised me too. They weren't the people whom I'd have said were my best friends. I now have really understanding friends, well, most of the time - they are teenagers after all!

From day one, the school refused to send newsletters, homework, cards or invite me in for the school photo. It was like they'd written me off. I wanted to show them that I still mattered and was still exceptional but in a different way. They wouldn't mark my work. They didn't really want me anymore.



The doctors were giving cures which were disproportionate to the seriousness of my symptoms. One suggested ½ an hour exercise a day would cure me (in other words, being well again!)

My parents were keeping everyone informed as no one spoke to anyone else. Eventually they complained to the School Governors, Council, local MP and put in for a Disability Discrimination Tribunal. Changes were made to school procedure so that certain mistakes in child-care and pastoral support would never be made again. Shortly after, one of my friends was hit by a car and, like me, put in Intensive Care. They had cards, phone calls, work and newsletters sent home. I'm proud that things will be better for others, because it would all have been for nothing otherwise.

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

Cover Picture : What did the policeman say to the scarecrow? 'Worzel this then?'