

# Mini Vision

## POST-A-POSTER CAMPAIGN : STOP DAMAGING EXERCISE THERAPY FOR CHILDREN WITH ME



We invite you all to join in our 2011 awareness campaign to warn about inappropriate exercise for children with ME.

We are sending you a poster that can be displayed or used as a leaflet to spread information.



Over time, children with ME generally become stronger, fitter, and naturally more able to join in activities of all kinds. That is the nature of healing. The body is built to self-heal, whether it's a cut or a broken bone. With patience and care, children are very resilient. But families have been telling us for years that if their children have been pushed into graded exercise or graded activity therapy to build them up before they were strong enough, they suffered adverse effects.

This is still happening. Many therapists and medical practitioners still advocate these therapies. Similarly, children pushed into graded school attendance

too soon typically relapse; in that connection we have noted your comments on *The Brief Questionnaire* (2010) which is still online for anyone wishing to complete it.

Publicity in *The Lancet* and the national media recently gave the impression that a trial involving graded exercise therapy (PACE) was a great success. The actual results were very modest, and it is widely disputed whether the people in the trial were actually suffering from classic ME. Along with others, we are objecting that certain measures of effectiveness promised by the researchers were not published.

A subsequent study has come to opposite conclusions. Do remember that it is the patient's right, and in the case of children, it is the family's right, to accept or decline treatment. In the end, you know your own child best.

Kindest regards,

Keith Harley  
Chair of Trustees

# Does your Inbox receive Jane's personal email Alerts? 2011 : My Year of the Net



These days, most families registered with the Trust are online. So this means I can make sure you're right up to date with my news. All I need is your email address.

In January I alerted members to a paper by David Sampson, where

he examines work by one of the PACE trial authors - Sampson argues that the conclusions drawn were not supported by the evidence.

In February I sent you all a link to my letter in *The Guardian* where I quoted the latest research into GET and CBT for people with CFS. That study reported worse physical function and bodily pain scores as a result of

treatment (*Clinical Rheumatology*, 15 January 2011). My letter is still online: [www.guardian.co.uk/society/2011/feb/24/truth-about-exercise-and-therapy/print](http://www.guardian.co.uk/society/2011/feb/24/truth-about-exercise-and-therapy/print)

Then, in early April, I invited you to Shrewsbury for my talk: *Do Treatments for ME work?* on May 7 at the Shropshire ME Group Annual Conference. I also sent details of some designer decorated paper going free for

members - I hope those who ordered it have had fun using it. If you'd like some, we have a few packs left.

To get my alerts, type your email address into the box at [www.tymetrust.org](http://www.tymetrust.org) or email me a personal message on the Contact Us form. I look forward to keeping in personal touch with all of you.

All best wishes

Jane Colby

Executive Director



**Coming soon at  
[www.tymetrust.org](http://www.tymetrust.org)**

Beautiful Spring photos in full colour by our Young Photographer, Sarah Coulbert.

*Sarah  
with our  
cuddly  
Highland  
Cow,*

*made by Katie Durben, Tymes  
Trust Friends Coordinator*



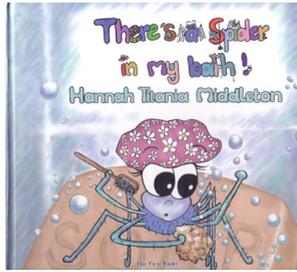
*Alice  
Gregory  
(age 5)  
coloured  
Susie's  
pictures*



# How you can join in

## Hey Guys!

Only about one in three cases of ME occur in men and boys, so we have fewer males than females on our database. But we like to feature you so do send us all your news. We were delighted to hear from Russell Meakin, who's made such a success of his graphic design business and now designs our posters. And at the other end of the age spectrum, 6 yr old Boris Cox has made a YouTube video about ME. Pat Williams writes: 'I expect you have seen this - but it's too good to miss if you haven't!' You can watch it at [www.youtube.com/watch?v=lz1VQcjpg7s](http://www.youtube.com/watch?v=lz1VQcjpg7s).



## There's a spider in my bath!

Seb loves this story book by one of our members,

Hannah Titania Middleton. Would you like it as a gift? Hannah says, 'I hope whichever member gets the book enjoys it!' Just write a letter saying why you'd like it. Seb will choose the winner...

*Send us a photo of you with your Teddy to win a Dalmation suit like Boris's*

## Sebastian's Travels

I've been out and about. My 6-year old friend Boris named our Christmas bear Harry (very royall!) when we stayed with him over the festive season. After we came home they missed each other, so we let Harry go back to live at Boris's place. Aaah.

Then I had fun on holiday at

Lynette Connolly's. 'This is Seb looking outside on a nice day watching the birds' says Lynette.

Would you like me to visit you? I've got a taste for travelling now... and I rather like posing for the cameras...

*Looking out of*



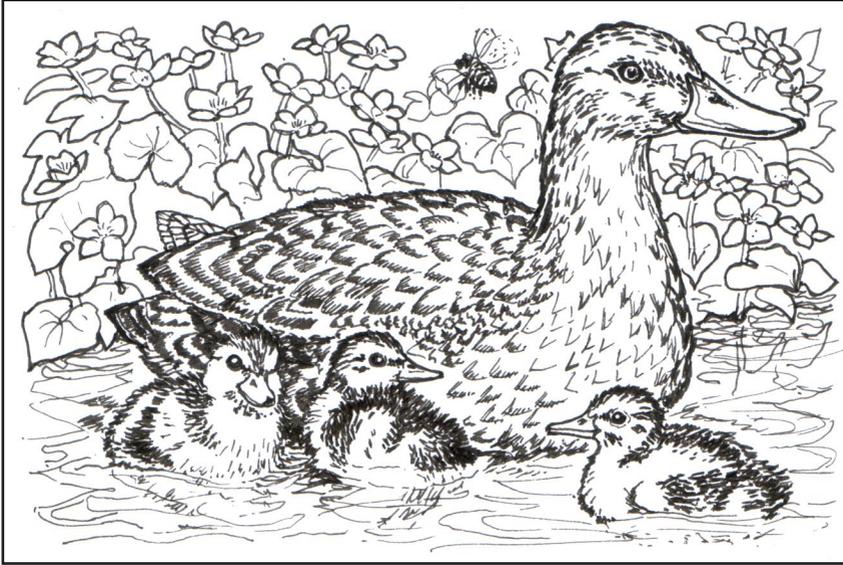
*Lynette's window*

*Boris let Harry and me make a snowman*



**COLOUR SUSIE'S  
SPRINGTIME!**

# Things 4



U2D0

Look inside for more ways you can join in!

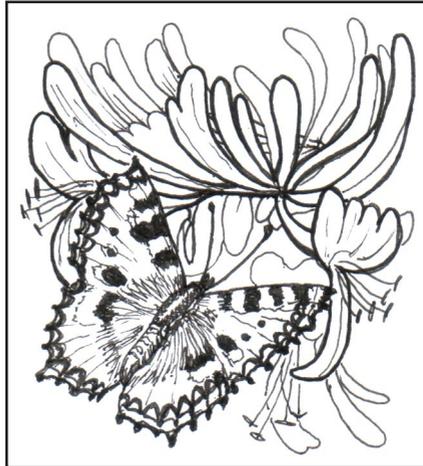
We think colouring is very therapeutic when you're not well!

Colour our ducklings and butterfly and send them back to us for a prize. We'll also publish them, space permitting.

Parents can help if you're too ill to do it by yourself. We select prizes so no-one's too young or too old to join in.

Name .....

Age .....



Read Jane's new column, find out who Seb went to stay with and see Alice's artwork (age 5).

## WELCOME TEAM

*Join our new telephone Welcome Team. No special knowledge required and you can do it from home. Parents or young people over 18. Call 0845 003 9002 for information.*