



# Russell's Report Spring 2015

I'm pleased to be bringing you more of our news and fun things to do. Turn over for advice on vaccinations, and Mr Harley writes about Summer weather. Russell

## READ JANE'S STRIPEY SOCKS BLOG

[methenewplague.net](http://methenewplague.net)

On her Stripeysocks Blog, Jane analyses ME and other issues. Look for these recent titles:

### THE CLINICAL IDENTITY OF MYALGIC ENCEPHALOMYELITIS

"Not many people will have missed the hooah about SEID – Systemic Exertion Intolerance Disease – as a proposed new name for ME/CFS."

### IT'S THE IMMUNE SYSTEM, RIGHT?

"Why am I not surprised that Mady Hornig and Ian Lipkin's research reveals that ME goes in stages? I've been telling people that since the 1990s."

### WHAT DO WE KNOW ABOUT SEVERE ME?

"We must not hide away the unpalatable truth, that some people suffer continually in darkened rooms unseen by the world."

### 97% : A SIMPLE EXPLANATION?

"Sometimes there is the simplest of explanations when an announcement doesn't make sense. It's like a fault in a garment; once someone points it out, you wonder how you missed it. And after that you see it all the time!"

## TYMES TRUST YOUNG OFFICERS

Isabella designed a new sticker for our collection boxes. If you're collecting for Tymes Trust, let us know. We'll send you a sticker for your box.



Fabian McDonald (9) coloured our Christmas card. Well done!



Lucy (12)

"I really enjoyed colouring this in as I love doing crafts!"



## YOUR PRETTY THANKYOU CARDS

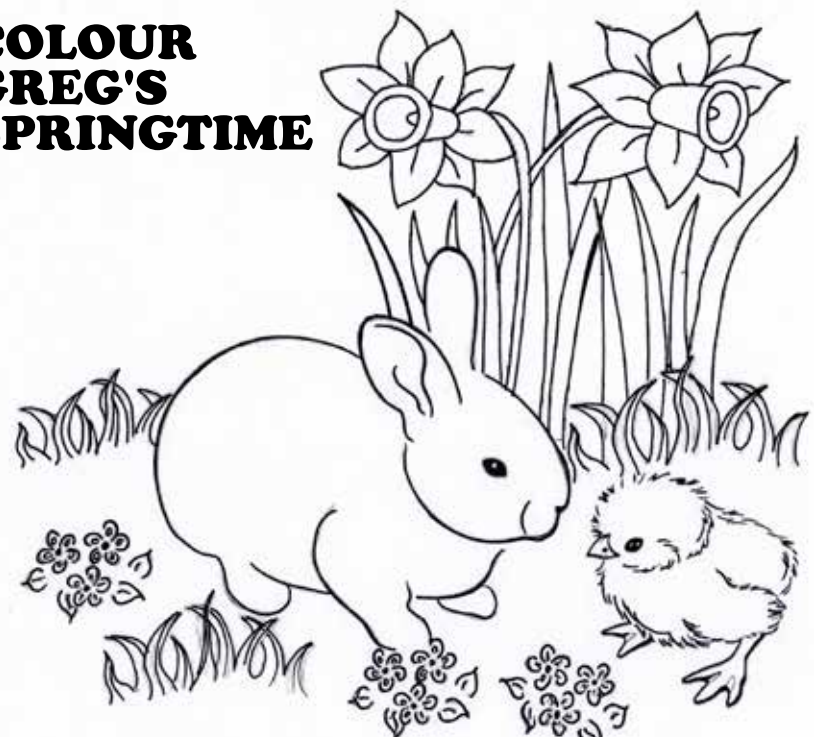


Prizes for colourings until we run out! Post to: Tymes Trust, PO Box 4347, Stock, Essex, CM4 9TE



Ben, Lewis and Arron designed Twitter posters: "NEVER SUSPEND YOUR OWN JUDGEMENT says Tymes Trust" See them also at [facebook.com/tymestrust](http://facebook.com/tymestrust)

## COLOUR GREG'S SPRINGTIME





## SUMMER AND ME

Here I am reminding you that summer is just around the corner. Children with ME who are well enough to venture outside can benefit from wearing a hat with a peak, like mine, to shade the eyes. A hat also keeps the head cool, helping to avoid a headache. ME generally makes eyes light-sensitive so sunglasses are important too. (I took mine off for the photo). Taking frequent drinks is also good, so as not to get dehydrated. And don't forget the sunscreen. Gentle shade is often better than direct sun if you have ME. Have a lovely summer.

**Keith Harley** Chair of Trustees



## VACCINATIONS AND ME

The Tymes Trust Advice Line is often asked about vaccinations. Parents of children who have ME clearly need to weigh up the potential benefits of any immunisation against the possibility of an ME relapse as a result. Not immunising children against a serious illness could mean they contract a full blown case of that illness itself. What to do?

Firstly, let's consider a straightforward decision - your choice of family holidays. When your child becomes well enough to travel, you could simply avoid choosing destinations for which a vaccination is needed. Many parents of children with ME prefer to holiday in the UK, as it is easier to return home if the journey turns out to have been a mistake. Travel can be hugely exhausting and exacerbate symptoms.

Other decisions are harder. Some people point to cases of ME that seem to have actually started with a vaccination and they are understandably concerned. In practice, we are told that reactions to vaccines are rare. So is there another reason why a vaccination could have provoked a case of ME, other than a reaction to the vaccine itself?

It turns out that there is. It is all a matter of timing. We thought we would share with you the following information from the famous microbiologist and ME specialist Dr Elizabeth Dowsett. She explained what can happen if a child is given a vaccination when their immune system is already busy dealing with another infection.

If a child catches a bug such as an enterovirus (these are very common and can present in a number of ways eg sniffly cold; tummy upset; flu-like illness) complications can result if the immune system is distracted by the introduction of a vaccine. The body's ability to deal effectively with the bug it is already fighting can be compromised by this new demand. So some cases of ME may have started in just this way. A sort of immune-system overload. And some relapses may happen for similar reasons.

There is huge pressure in schools to stick to vaccination dates and targets. We know of mothers who have had huge trouble in postponing their child's vaccination date when they developed a cold or were otherwise unwell. Children are not supposed to be vaccinated unless they are well. Yet it appears that parents are being made to feel that they must accept the date given. Arranging for an alternative date may be difficult, but if the child is actively unwell another date should be offered. In a long term illness the choice may be difficult and medical advice can be sought to help with the decision.


It is important to remember the 'risk-benefit' equation. If someone is bitten by a dog, they are offered a tetanus booster. Most people would choose the booster, even if their ME might temporarily worsen.

**Jane Colby** Executive Director

## KEEP UP TO DATE WITH US

 [facebook.com/tymestrust](https://www.facebook.com/tymestrust)

 [@tymestrust](https://twitter.com/tymestrust) and [@JaneCColby](https://twitter.com/JaneCColby)

 Register at [tymestrust.org](https://www.tymestrust.org)

