

Tymes Tidings



I'd like to start this Chair's letter with a resounding 'Thankyou!' to our volunteers and supporters. Each of you forms a vital part of our work. You help us ensure that the voices of children and families are heard. You are spreading our poster campaign on Facebook and Twitter, displaying prints in libraries, raising funds so that our support to families can continue.

Our focus on campaigning with such bold posters has been well received by both public and parliamentarians. We took our latest poster to Huddersfield, where our Executive Director was on the ME Question Time panel. Suzie from our Advice Line Team came along to advise visitors to our stand.

At a political level we continue campaigning both for the educational needs of children with ME and against misguided social services investigations

of families. Children's Minister Tim Loughton has now requested further details from us, so he can truly appreciate families' experiences. We are grateful to the MPs who constitute the present All Party Parliamentary Group, and to the Countess of Mar, for taking the bit between their teeth on these controversial matters.

Our Executive Director and the Director of the Nisai Virtual Academy are about to meet with the Countess and the Department of Education. It is a tragedy that administrative officialdom has blocked many potential virtual students in the last two years.

Turn to the inside for more news - and parents, please help your children with all the special activities.

Keith Harley
Chair of Trustees



Jane Writes...

I've just had an excellent meeting with the Dept for Education and the Nisai Virtual Academy in the House of Lords, kindly arranged and led by our patron the Countess of Mar. We are together striving to remove barriers to virtual education caused by 'red tape'.

Education is a huge problem for children with ME. Do consider filling in our *Explain Your Abilities* questionnaire for the school and request a formal assessment of your special educational needs (SEN). The government's new SEN Green Paper is called *Support and Aspiration*. Current thinking is that all young people, including those who are disabled or who have SEN, should have the best opportunities and support so that as far as possible they can succeed in education and their careers, live as independently and healthily as they are able to and be active members of their communities. We still hear of schools worsening children's health and erecting barriers to education rather than removing them. Is your school one of the good ones?

This year we've increased our online services. By the end of 2011, I'll have sent you 12 email Alerts and Statements plus three postal mail-outs in A5 format. This made good use of your donations, as post and printing costs have soared – and we also like the colourful little booklets. I love seeing your colourings, letters and emails, and try to ensure



that all are answered. Let us know if you don't hear back. Remember to put a large letter stamp on A4 letters or it costs us £1.19 to collect. Check your spam box if you don't see my emails. You can follow me on Twitter @JaneCColby or read my tweets at www.tymestrust.org – get updated and read some wry comments...!

Jane Colby, Executive Director

Explain Your Abilities is at www.tymestrust.org/pdfs/explainyourabilities.pdf

Fact

Present law states that for over 16s 'LEAs must secure enough education and training for young people up to age 19 to meet their reasonable needs, having regard to any learning difficulties...' (Apprenticeships, Skills, Children and Learning Act 2009 (c22) clause 41.)



Our lovely Advice Line Team is just a phone call away on 0845 003 9002. Tymes Trust is run entirely by volunteers, including me. Would you like to help?

Book Launch

Hannah Titania *A True Fairy Tale*

My Waterstones book tour began in Glasgow. Children came as fairies and had fun colouring, getting their books signed and listening to the Celtic harp. They were given fairy stickers and cards; many said they'd try making fairy houses! I also read in schools. The nursery children loved *There's a Spider in my Bath!* and *Little Lost Seal Pup* and sang *Itsy Bitsy Spider* to the harp. The older ones were fascinated with the fairy myths and legends. Many had never seen a forest or a wild deer. I was delighted to bring fairy magic into their lives. They gave me *Itsy* colourings, poems and illustrations inspired by my book. I like to think I may have inspired a future author or illustrator! Manchester's Trafford Centre is like a city. A film crew was making a documentary about my family and me; I had a mic' and sang with the harp. I used a Salvi, like Orlagh Fallon when I met her. In my opinion they are the most beautiful sounding harps. Then I got tonsillitis, was very ill and in pain, but I had planned for rest days. I saw a doctor and my sister looked after me, driving, carrying, moving the harp. My Dad came to England as well - I couldn't have managed without them. I am lucky that my family understands about ME and supports me. My tour ended with the Islay Book Festival,



where I live. I have had ME for almost seven years. At first I had to spend all my time in bed. Some days I still wake up and think 'I feel so unwell, am I going to get anything done?' I am so happy that I found Tymes Trust and that it is helping so many young people with ME. I hope I can inspire other young people with ME to follow their dreams.

Hannah Titania Middleton

Win a signed, numbered Gold Limited Edition of Hannah Titania A True Fairy Tale. Two runner up prizes of the first, purple edition. Hannah says: 'Draw a fairy or a mythical creature, or write a fairy poem. I will choose the top three. I know how creative all Tymes Trust members are and can't wait to see what you come up with!' We will also print selected entries.

Russell's Roundup

Young Hearts Day 29 November

Our 2011 Young Hearts Award goes to Royal Wootton Bassett School for their support and kindness to children with ME. Nomination: the Barnes family. A Young Hearts Bag goes to their daughter.

Bag modelled by Isabella, daughter of Tymes Trust volunteer Anita.



Odyssey Anniversary

It's the 10th anniversary of the 2001 Odyssey, a marathon horseride from Lulworth Cove, Devon, to Edinburgh Castle. We used the funds on the Dundee research that showed evidence of persistent viral infection in children.



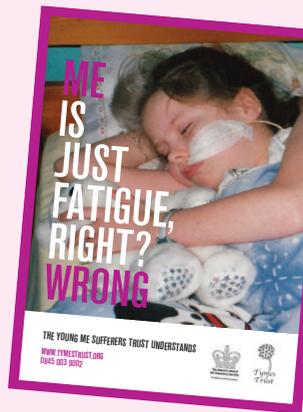
Poster Campaign

Please please may I have more posters? Your posters made such an impression on our local air ambulance man that I asked him to share with his crew to create awareness of children's ME. Love Joy xxx

Poster leaflets cost £3.35 for 10 inc p&cp

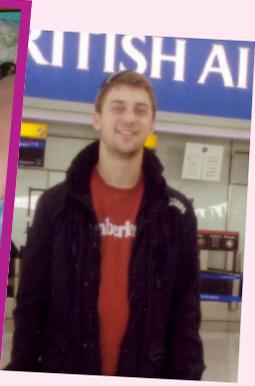
From Seb's Archives

I had a cool holiday with Chloe and Amber. Can I stay with you next?



William's news

My ME is getting a little better and I am able to do just a little more so I am beginning to have hopes of better health again...



David moves on

David has flown to Brazil to be best man at a friend's wedding and teach for a year. We appreciate all you do to raise awareness and

the many ways in which you continually support young people with ME. I enclose £100 for your funds. God bless you all.

Helen Leeds.

David, 24, struggled into school from age 9-12. A caring paediatrician said it would be more beneficial to study at home, resulting in in top grades, college, volunteering and foreign travel.



Photo of cute dog is by Lynette

Young Photographer

Our newest Young Officer, Lynette Connolly, in Omagh. Nextdoor's dog sends seasonal greetings: 'Woof.'

26+?

Just had my 26th birthday and received your letter. I've made a farewell donation and want to thank you for your support and for the lovely birthday cards you've sent me every year. It has been tremendously helpful and inspiring. I'm planning an exhibition of my photos: this is Little Pleasant Bay, Cape Cod, USA, It was still water and really peaceful.

Georgie.

Want to stay? Join our thriving 26+ 'family' of supporters who have access to all our services and from 2012 will be invited to our special events.



Mini Bookmarks

Here are 1250 mini bookmarks for Tymes Trust members...

Love from Hannah Titania

Did you find a mini bookmark in your Tymes Tidings?

Seb's Spread

I've got a double page spread again.
Yay! Well of course I have. I'm so
modest and good at everything.
So here we are. Ho Ho Ho.

Now, did you know that Russell's
done ALL of Tymes Tidings for us?
Naturally, it falls to me to thank him.
Mark (who usually does our magazines)
has been driving racing cars. When
I heard, I said 'Yeah, right,' but he's
promised a photo for next time...



Seb's Easy Peasy Comp

Snow and stars, a wintry night
Santa's ready, wrapped up t _ _ _ _
Bobbled hood and coat of red
While the world is snug in b _ _

Presents ready in his sack
Many hours till he's b _ _ _
Sleigh and reindeer standing by
Till off they go and up they f _ _

Travelling over land and s _ _
What's for you – and what's for me?!

*Fill in the missing letters. Cuddly toys
waiting for correct answers. Remember
– it's got to rhyme. Write to me or email
using the Contact Us form at
www.tymestrust.org.*

*Oh, and Jane says hi to Frances,
who sent her the card for my Comp.*

*My special friend Lady Elizabeth Anson,
cousin to the Queen, and me. She tells me
she loves all your work and enjoyed
meeting some of you at the House of Lords.*



My Art Collection

I've been collecting your great colourings and artwork. Being an artist and a poet I must have art and poetry on my pages. Send me more!!

PS Paige Ann won the *Name the happy hedgehogs* comp!

Springtime



by Grace (15)



Cosy Fireside



by Abigail (16)

Tymes Tidings

Country Stuff



by Lynette (21)



by Stephanie (10)

Mr Pricklepants & Tyme



by Paige Ann (13)





Colour Mary's Russian Dancers

In the past, Jane produced many dance dramas for children. Mary, her mum, was an artist and sketched this group of boys and girls performing Russian dance in bright costumes. Jane would love to see your coloured version and has lots of prizes waiting. Don't forget to say if you'd like yours published.

Name & Age

*Send to: Mary's Dancers, Tymess Trust,
PO Box 4347, Stock, Essex, CM4 9TA.*

Jane's tips: 'Felt pens work well on shiny paper. It's best not to fold your picture, and use a stiff envelope.'