



2014

# Tymes Tidings



Volunteer Isabella Williams with her Young Hearts gift.



thank them. Our invitation to parents to nominate their children for gifts was certainly popular, with many requests arriving and many parcels sent out.

We are already planning for 2015 and we hope you will take part in our latest project to ensure that injustice and discrimination towards children with ME are addressed, and that good practice is recognised.

Kindest regards,  
**Keith Harley - Chair of Trustees**

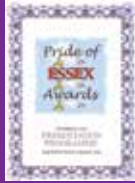
*Keith Harley*

We're approaching the end of our 25th Anniversary year, and what a year it has been. We have given many presentations and taken part in events, as you can see in this issue of Tymes Tidings.

November 29th, Tymes Trust's Young Hearts Day, was marked by supporters and parents posting virtual candles, or photographs of their real ones, on Facebook, Twitter and elsewhere. We sent surprise gifts to young members whom we know are going through a hard time, and to young volunteers. Our Advice Line Team, who give up so much time to helping our callers, were themselves sent a pretty pencil to mark the occasion and



## Pride of Essex Award



Jane says:  
"It was an amazing evening – apparently I was nominated by seven people. I'd like them to know that the Trust has benefited as I have donated my £250 Award. Thank you so much."

Having recently attended the 2014 Pride of Essex Awards Ceremony, at which Jane Colby received an award, I am delighted to have the opportunity to offer to all the supporters of the Tymes Trust my best wishes and warmest Christmas greetings.

I have long been an admirer of the Trust's work and Jane's award is a well-deserved tribute to all that it does to support young ME sufferers. I hope that you will all continue to support the cause and do what you can to spread the word further.

Lord Petre  
Lord Lieutenant of Essex



Left to right: Keith Harley, Tymes Trust Chair; Jane Colby, Tymes Trust Executive Director (Ultimate Pride of Essex category); Dave Dennison, Managing Director of Main Sponsors Directa UK Ltd.



Tymes Trust volunteers and patrons at the House of Lords



## House of Lords Learning Awards



Lord Clement-Jones CBE

Hosted by the Lord Clement-Jones CBE, Tymes Trust Founder Patron, and held with Nisai Learning in June, our 25th Anniversary month.

“A 25th anniversary is really special, isn't it? It's something to celebrate. Or is it? If we didn't have this dreadful disease to contend with, if there were a cure, so that children didn't have to spend years of their life in darkened rooms, in pain, Tymes Trust wouldn't be needed. But until then, what we are celebrating is the success of young people succeeding against the odds, and the dedication of those who are helping them. And there are presentations to be made.

the person they speak to, someone who knows from personal experience what they are going through. We also have Trustees here, and Patrons. Our newest patron is John Whittingdale, our local MP, who's often on our screens because he chairs the Select Committee on Culture, Media and Sport. We also have some of the professionals who work with the Trust. A great team. And of course, we have our partners, the CEO and staff from Nisai Learning.

“So let me give you a theme for our 25th anniversary year: FIGHTING INJUSTICE. It's a big part of our work. [...] If an adult doesn't listen, isn't kind, doesn't help, they remember. It can colour their whole lives. But just as children remember injustice, they also remember those who really have listened, and have helped them.”

*From the speech  
by Jane Colby available at  
[www.methenewplague.net/  
blog.html](http://www.methenewplague.net/blog.html)*



Jane Colby and Dhruv Patel,  
CEO, Nisai Learning

“Everyone at the Trust works pro bono. Along with our guests, we have some of our Advice Line Team here. All of them are either parents of young people with ME, or people who've had to cope with ME themselves. That's because it's so important, when people call us, that they have confidence in



Terry Waite enjoys tea

# Tymes Tidings

## Russell's Roundup



It's that time of year again. I am happy to be setting out another encouraging Tymes Tidings! Here are some of the many people who've been involved with the Trust this year.



Flowers to thank us



Jane gave a two-hour training session to education students at Bishop Grosseteste University in Lincoln. Julia Lindley-Baker writes: "Thank you for the time you spent at BG. Everyone appreciated this."



Question Time panel in Oxford



The OMEGA host group in Oxford writes: 'We would like to thank you for your valued contribution to MEA Question Time. Many people said they enjoyed the event and found it very interesting. It was lovely to see you; thank you for giving up your time and energy to give us the benefit of your knowledge and experience, which was much appreciated. Thank you also to those people who assisted you, both beforehand and on the day, or who gave up their time in other ways.'



Summer holiday at Kynance Cove

To Jane Colby and Crew: recharging our batteries. Our daughter is doing a good job with her pen-pal, they have a lot in common, it's great. We thought it would be a good idea to send you this card, if only to remind you all what a fantastic job you do keeping HMS Tymes Trust afloat, and that you are very much appreciated. Keep up the good work. From The 3 of Us (the Pritchards).

## Thanks to our fundraisers



Thanks to Writhlington School

Jorja Mannings, mum Emma and her school together raised £900 for the Trust's work. A magnificent joint effort and so much appreciated.



We know who you are!

Mystery £200 donor writes: 'Thank you so much for all you do for those that suffer from disbelief! Here's a little something to help make those children's lives a little brighter this Christmas :)'  
Thanks for your generosity.



**PARKLANDS  
HIGH SCHOOL**  
LEARN | RESPECT | APPRECIATE | ACHIEVE

Amy Davis' school writes: 'Please find a cheque for £500, which was raised by staff and pupils in support of Tymes Trust.' Thank you everyone. Amy's music teacher Paul Willsher was given a Tymes Trust Young Hearts Award Certificate last year, for his support and help.



Help me. Help us 'see' ME

Amy Hall wrote on the You Caring fundraising site: 'Do you ever look in a mirror and wonder what you appear like to other people? Many people have looked at me, very few have seen M.E. Apart from the ones who have taken the time to listen and advise [...] they are Tymes Trust. I have ME, so I'm giving back by making a bold (very difficult for a teenage girl) statement to the world. I am not going to look in a mirror for the whole of October. This statement says 'although ME is an invisible illness, it is not going to go away if you ignore it.' Neither am I. Please give generously or just pass on the word about my mission.' Amy raised an amazing £368. Thank you Amy.



Chloe Halstead's success

I entered my photo of Fairhaven lake in Lytham into the Lancashire Life calendar contest. I was in the top twelve that got published.

Ben Pearson's mum Julie raised almost £1300 for three charities and we were delighted to be given a third. One of the events was a 'swim the channel' in a swimming pool! Ingenious. Julie writes 'Your charity has been a great source of information for us. We have read your documents with interest, especially on home-schooling and GET.'



# Tymes Tidings

## Young Hearts Day was 29th November



Tymes Trust's Young Hearts Day candle.

We lit a real candle and posted the photo: on Twitter @JaneCColby, @tymestrust and on our Facebook page facebook.com/tymestrust This is an open page that anyone may view.



Young Hearts Day gifts

**Tymes Trust resources:  
New for 2014. Free at  
[www.tymestrust.org/  
tymespublications.htm](http://www.tymestrust.org/tymespublications.htm)**



Ben Burgess and Isla Kidd star on our latest poster: 'No, you don't know best' and '25 years of Trusting Tymes'.



The Good Practice Guide to Education for Children with ME



Our False Allegations booklet can help to explain ME to people who might otherwise misunderstand why children can be ill for so long.

## Parent Perspectives

As well as sending out gifts, we chose Young Hearts Day to launch our final new project of the year; it will carry on through the early part of next year and we plan to report on it for ME Awareness Day 2015. You can find all about how to join in by reading our latest Alert at [www.tymestrust.org/tymespublications.htm](http://www.tymestrust.org/tymespublications.htm)



## Seb's Art Gallery

I've saved these colourings by Jorja Mannings and Fabian McDonald ALL YEAR to go in my Art Gallery. Why not send me the ColourME Card in this issue of Tymes Tidings?



Mr Harley's Annual Gift of Bears (not!)



Fabian McDonald



Jorja Mannings

Mr Harley got you so many baby snowmen last year (instead of his Annual Gift of Bears) that some of them are still here! Causing no end of trouble. Write to Mr Harley if you think one would like to come and live with you. They're snuggly and fit right into your hand. Or your pocket.



Cooking is art too, isn't it? Look at the Anniversary Gingerbread sent to us in June by Shannen Dabson. Yum. We all enjoyed it, but I knocked off some of the silver balls. Ooer. They did say '25' when they arrived...



Goodness, we also have some cute puppy keyrings. Where did they come from? Write to Mr Harley if you'd like one. Ask someone to write in for you if you're not well enough.



## Seb's Christmas Comp



I love getting messages on the Contact Us form at [www.tymestrust.org](http://www.tymestrust.org) and I love getting letters through the post, so you can send me the answers either way.

PS Grown-ups can join in and help. We don't want them feeling left out do we?

Look how I grew! I bet no-one remembers me when I was little. I started out as resident Website Spider, I'm Tymes Trust poet, artist, children's gift adviser (I can turn my eight hands to most anything) and yet I'm SO modest. Amazing. Most of all, I love Getting Involved.

Now, here's a little competition. Fill in the blanks on my poem. One letter for every dash. And it's got to rhyme.

Email or post your answers to 'Seb's Comp' at Tymes Trust. Include your age and details. I can't wait to send you a prize. Wahay!



The Countess of Mar

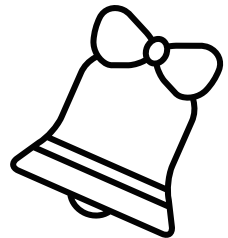
### "Do you know what ME is?" I asked...



Merry Christmas to you  
I went to the z \_ \_  
I asked what ME was  
But they hadn't a c \_ \_ \_



Merry Christmas to me  
I crawled up a tr \_ \_  
I asked what ME was  
But it couldn't tell m \_



So I phoned the Countess  
Who smiled and said "Y \_ \_  
ME's neurological  
Not just 'CF \_ '!"