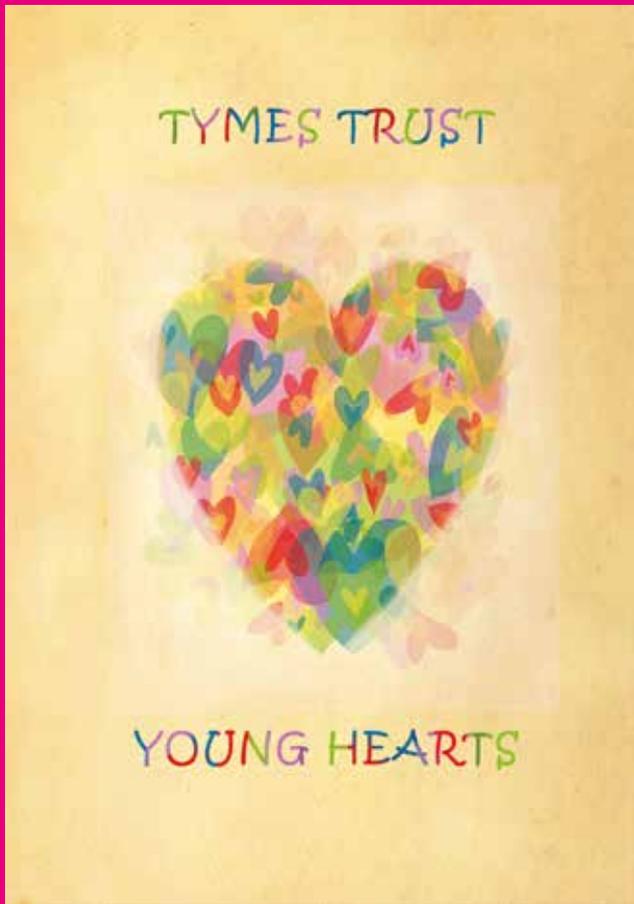




2015

Tymes Tidings

This year's Young Hearts Day on 29th November saw us posting out sack after sack of Young Hearts cards and gifts! Turn inside to find out more...



Young Hearts Design by Kathryn, Tymes Trust Young Officer



Tymes Tidings

Tymes Trust's Young Hearts Day 29th November



Tymes Trust Candle



Jan's Candle



Lorraine Ann's Candle



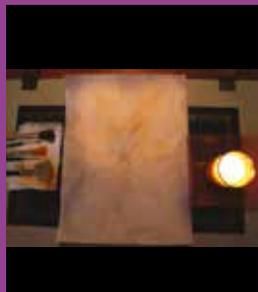
Ellen's Candle



Katie's Candle



Rfk's Candle



Sakara's Candle

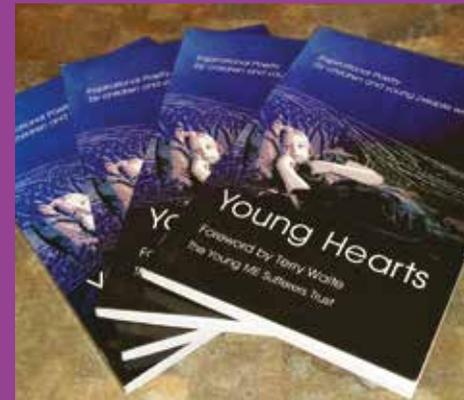


Sophie's Lantern



ICC's Candle

When darkness fell on Young Hearts Day, the Tymes Trust candle was lit to remember children and young people with ME everywhere in the world. We posted it on Twitter and Facebook, and it began its journey around the net as people shared it with their friends and ME groups. At the time of writing, just two days afterwards, our Facebook post has been seen by 5,777 people. We haven't checked on Twitter yet! We invited everyone to join in and light their own candle – and they certainly did, as you can see.



My daughter dressed herself today "That's very good" I hear you say "If she is two or nearly three." She's thirteen - and she has ME. **From Young Hearts**

Duncan Cox wrote a moving account of the first Young Hearts Day when Terry Waite CBE launched our Young Hearts book of poems in Warwick Castle, in 2004. The book is still available from us for £7.95.



Pippa, Tymes Trust Young Officer

This year we sent out a record number of Young Hearts gifts for our young members – and even some non-members too. Our Executive Director Jane Colby sent out one of her email Alerts and requests started coming in from parents. They went on and on coming in until we thought we might run out of gifts! But there were enough, and no-one was disappointed. Pippa, Tymes Trust's newest Young Officer, and Anita, Jane's assistant, wrote cards for everyone and mail sacks were filled. Thank goodness we only do this once a year!

Lighting candle to remember & pray for all young people who are battling #neuroME today @tymestrust #youngheartsvigil

Katie's Tweet

Are you going to light a #candle for @tymestrust young hearts day? My brushes/candle watercolour/real candle #mecfs

Sakara's Tweet

@tymestrust Thoughts and prayers for all our young folk with ME

Lorraine's Tweet

A candle lit for all the isolated kids out there who suffer with M.E. Hugs and kisses x @tymestrust #youngheartsday

Ellen's Tweet

Don't forget to sign up for Jane's email alerts at www.tymestrust.org. Type your name into the box at the top, and you'll receive an email inviting you to click and confirm. Then you'll be on the list. (Don't worry – we don't use your emails to send you spam, or fundraising demands.)



We've been sent a Christmas card of "Westminster in The Snow". Thank you Marie!

The Trust continues to be part of the Countess of Mar's Forward ME group, which is by invitation only. We meet in the House of Lords and we are happy to make our regular contribution.



Jane's Twitter Face

2015 has been another busy year for the Trust.

You can keep up with us daily on Twitter @tymestrust and @JaneCColby (you don't have to tweet, you can just follow us!)

Our Facebook page www.facebook.com/tymestrust
Advice Line
0845 003 9002

Our Advice Line has a new system. Our small dedicated group of advisers who work pro bono (as do we all!) had increasingly been finding themselves waiting by the phone during Advice Line hours, and then also needing to make "out of hours" callbacks to people who emailed or left a message.

So I recorded a personal greeting on our voicemail inviting all callers to leave a message telling us why they called, and we now arrange callbacks for everyone (don't forget to suggest some suitable times for you). This has the advantage for callers that we can get the necessary information ready, you get a call at a convenient time and do not incur call charges for the discussion, and we can make best use of our kind volunteers. The system has been working well, but sometimes Debbie and the Team try many times to get through, but no-one picks up, perhaps because the caller display reads "number withheld". Giving us times

when you will be available should help with that, as you will not be worried that it is yet another annoying spam call!

In the Autumn I was on the panel at the MEA Question Time event held at the Tiffin School in Surrey.

Over 90% of our calls concern problems with schools. We have been working hard this year to improve our members' individual schools' understanding of ME, with talks and phone consultations. We explain why children with ME need time at home, on a part-time timetable, perhaps learning with a home tutor or virtual education, or even not studying while they are severely ill. Some parents home educate and we can discuss that with you too.

If you would like to be part of the Team, we'd love to hear from you on the Contact Us form at www.tymestrust.org

Jane Colby
Executive Director



Creating memories of the day



Our Queen's Award. information table, cakes



Summer Parlour ready for our guests



We love your cards!



Trustees, volunteers and guests

Ingatestone Hall

In ME Awareness week we held an Afternoon Tea at Ingatestone Hall. Trustees, parents, young people and guests were welcomed by Lord Petre, Lord Lieutenant of Essex. We presented our ME Awareness Statement **Equality and ME** to address injustices described to us by parents. Some of you have been threatened with fines and even prison for allegedly allowing truancy from school, and generally disbelieved. Show this Statement to schools and other professionals to help ensure that your children are not discriminated against.

Equality and ME
www.tymestrust.org/pdfs/meawareness2015.pdf

Priscilla, parent

If we did one thing right it was not to push them to do more than they were able early on.

When they were ready they added activities as they could, and neither had a major relapse.

Kathryn, Tymes Trust Young Officer

I was so happy to read about the popularity of Young Hearts Day in your email. I can't thank you enough for everything the Trust did for me and continues to do for young people. You will probably understand what I mean if I say that ME can be a very isolating illness, and Young Hearts Day is a wonderful opportunity for us to remember we're not alone.

Join our 26+ Group

Parents can now join our 26+ Group. We started it for young members who want to stay with us after our "leaving age". Then we opened it up to parents and supporters. You get invitations to our events, and receive additional mailings. £10 per year. Join at www.tymestrust.org/registrationform.htm



Tymes Tidings

NEW! Seb's Family Art Certificates



doing well, and point out where they're going wrong. Join in if you feel up to it. Or we won't mind if you do it on your own. But it's lots more fun with everyone – brothers, sisters, the cat... If you all want to make it bigger for colouring, scan it and print it out larger. Be creative.

When you're done, fill in the form opposite, tear off the back page of Tymes Tidings and post it to us at

Seb's Family Art Certificates, Tymes Trust, PO Box 4347, Stock, Essex, CM4 9TE.

(It's best in a big envelope so if we publish it there won't be creases all over it.)

Send an extra stamp if you'd like it back.

Looking forward to sending you one of Seb's Art Certificates for your wall!

Merry Christmas. Love from Seb xxx

PS 26+ members can join in too. We know who you are!



So get your family busy on Greg's Santa. Mum and dad can do some, and gran, and grandad... You just sit there and tell them what colour to use, nod your head if they're



Little Seb (my little brother) is going to have a go at this. He looks just like me before I grew up.

Mr Harley's Cuddly Toys Collection



This year, I have a Collection of Cuddly Toys. If you would like one, email me on the Contact Us form at www.tymestrust.org or write to Mr Harley at

the Tymes Trust address. It's that time of year when it's easy to do rather too much. Don't wear yourself out! And have the best time.

All good wishes

Keith Harley,
Chair of Trustees



Mr Harley's Annual Gift of Bears (well, some are!)

Can you answer these questions for a prize?

Why does Little Seb look as if he's only got 7 legs?

.....
.....
.....

In Greg's Santa picture, where are the bells?

.....
.....
.....

Do you think Big Seb really has been a good boy?!

.....



Can you fill in all the blanks?

(One letter for each blank. Remember, it's got to rhyme.)

Santa's flying in his sleigh

Over the rooftops far _ _ _ _ _

Loaded with a bulging sack

It'll be empty when he's _ _ _ _ _

If you're still awake that night

Will you hear him? You just _ _ _ _ _

GREG'S SANTA RETURN FORM

DON'T CUT IT OUT! Tear off the back page and return the whole thing.

Name of Tymes Trust Member

.....

Address

.....

.....

Did you do the colouring on your own? Or Did you do it as a family?

.....

Who joined in?

.....

.....

Whose name do you want on the Art Certificate – yours or the family's? (eg Susan Smith or The Smith Family)

.....

.....



Tymes Tidings



COLOUR GREG'S SANTA

