



The Queen's Award
for Voluntary Service
The MBE for volunteer groups



TYMES TRUST 2022

Mr Harley's Christmas Letter

This year I'm writing you a Christmas letter for a change. I've just been going through my collection of prezies and I have all sorts of lovely little surprises waiting for you. Just send the young person's name, age and address on the Contact Us form at www.tymestrust.org and ask for one of Mr Harley's Prezies. We'll do the rest.



"Wrap up warm!"
says Mr Harley.
"We still have some
cuddly throws if
you'd like one."

While I'm writing about prezies, did you see our reminders on Twitter and Facebook about Tymes Trust's annual Young Hearts Day on 29th November? This is the day when we light a candle to remember all young people with ME and post it online for others to enjoy. You can see some of them in this letter. If you missed the day, it's not too late to request a Young Hearts Day card and gift. Posting her candle on Facebook, Sarah McLennan wrote: "Lighting a candle today for #YoungHeartsDay and all #kidswithME #pwme. Yesterday we borrowed a wheelchair and took Ceit to York Christmas Market, she also visited the cat cafe which she wouldn't

have had
the energy
for without
the chair,
so feeling
very
thankful."

NOW FOR SOMETHING THAT REALLY CONCERNS US

In view of some services for children with ME still apparently "prescribing" Graded Exercise "rehabilitation", we thought we would remind you that the new NICE Guideline (2021) clearly states: "Do not offer [...] any therapy based on physical activity or exercise as a cure" or "any programme that [...] uses fixed incremental increases in physical activity or exercise, for example, Graded Exercise Therapy." We would strongly agree as we have found that as the body recovers it is able to do more, not the other way around.

We have been shocked to hear of families still suffering child protection investigations when they decline these therapies or when the child does not recover as a result of them. I've even heard of some being told that they can't use a wheelchair to get about any more.

We sent out some key NICE quotes to our members on page 6 of Tymes Tidings 2021, which is on our website magazine page at www.tymestrust.org. You can refer doctors and others to these.





RENEWALS

I expect you'll have noticed that for some time we haven't been sending renewal fee requests to members of Membership Plus, which is for parents, supporters and any young people with ME over 26. In view of these tough times faced by families, we're continuing to waive renewal fees for the foreseeable future.

Beth got a prize for her beautiful colouring of Lucy's artistic sketch



REMINISCING

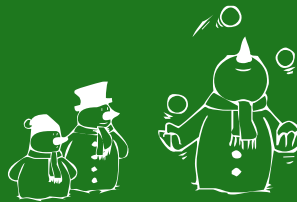
It is such a joy to remember the wonderful Reception at Windsor Castle when Jane Colby and I were received by the late Queen. This was a special event for selected voluntary charities and we were honoured to be among their number.



As the nation mourned her passing earlier this year, we were able to think back and be glad that we had had the privilege of meeting her.

Wishing you all well

Keith Harley
Chair of Trustees



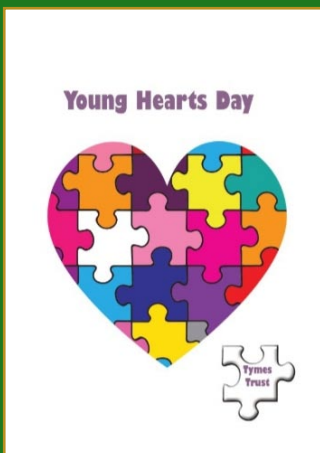
We're so proud of Jade Henson-Amphlett. We love to hear of all your achievements, and Jade has now heard that she has obtained her MSC Masters degree in Real Estate! Mum Suzie writes: "She has done so well, she was told she'd probably not ever get A Levels. Always so grateful to Tymes Trust for amazing sensible support and direction."



SuzieHenson-Amphlett @SHen... · 1d
Light a #YoungHeartsDay candle today to remember&celebrate the courage of &hope4 children&young people living with #ME &their care givers. My heartfelt #gratitude to @tymestrust for their endless support to my own &so many families. Honestly don't know where we'd be without them!



Young Hearts Day Cards designed by
Tymes Trust Young Officer Rachael



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Registered Charity 1080985



Jane Waters

Way back before FB when we were lost Tymes Trust was that candle in the darkness...thank you Jane & Team

