

Tymes Tidings

2017



The Queen's Award
for Voluntary Service

The MBE for volunteer groups



This year we are featuring the work of Tymes Trust Young Officer Fabian McDonald. You'll find his name popping up on several pages. It is painful for Fabian to write, as we know it is for many of you, so his mum Jean sometimes writes for him.



Fabian was driven all the way to Essex for our summer event in Ingatestone Hall. It took it out of him hugely, but he so enjoyed it. You'll find more about that inside. Don't let anyone tell you ME is 'invisible'. It's quite clear when someone with ME is 'fading'; they become pale, and it's all too obvious when they start to feel bad. All our

wonderful Advice Line Team have personal experience of ME, and our Executive Director suffered severely for years, so we do understand and care about you all.

Now turn inside for photos of highlights of the year and your artwork. Everything about Christmas is on the back - with a special TV celebrity Christmas message. Thank you Yvette Fielding!

Keith Harley
Chair of Trustees



AND I've been given a present! A big box of cute knitted minibears for you. If you'd like one, just email the Trust on the Contact Us form at www.tymestrust.org.



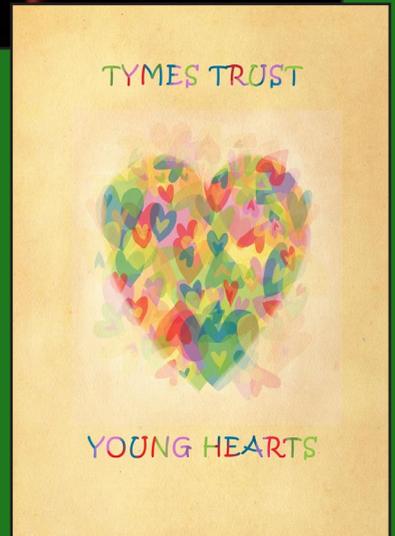
Tymes Trust's Young Hearts Day

29th November 2017

This year our Young Hearts Day was the biggest ever! It's the day we remember children with ME everywhere. People post a candle on social media, and parents can request a little Young Hearts gift for their child, even if they're not members. We loved your thank you messages. We're so glad to have brought a smile to the children's faces when they opened their surprise packages. If you want a reminder of the day next year, follow us on Twitter or Facebook and subscribe to our Alerts emails on our website www.tymestrust.org.



TymesTrust
#YoungHeartsDay





Rachael Marshall

I love how much you do for young people with ME and will always appreciate the support I felt I had just receiving the Christmas and birthday cards, magazines, and knowing I wasn't alone! Being now 31, doing the job I always wanted (teaching preschool), living on the other side of the world, and feeling 99% better (I still have to pace myself but I would say I am so close to "normal" it seems crazy to say how 15 years ago I couldn't even walk downstairs by myself properly!) I think Tymes Trust is fat too under valued and would happily shout from the rooftops how great you are 😊

Can you spot your candle here?

We didn't have room for them all!



 Nisai Learning
@NisaiLearning

We're supporting @tymestrust as today is #YoungHeartsDay, we remember #kidswithME everywhere



Jean McDonald, mum to Fabian, Felix and Francis, writes: "Young Hearts Day is such a lovely spiritual Day where we all connect and remember our children suffering with ME. Thank you for creating such a significant moment each year to raise awareness."



Your Artwork

Ellie (16)

We love to see your artistic interpretations of the designs on our postcards. Art Certificates and prizes waiting! Family and friends can help if you're too ill to finish it on your own.



Sarah (17)



Heather (19)



Emma (10)



Daniel (13)



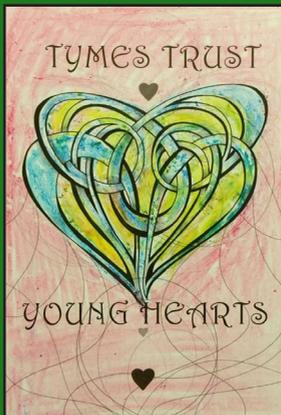
Seini (11)



Lauren, for Isla (12) who was too



Fabian (12)
Felix (17) and
Francis (14)



Heather (19)



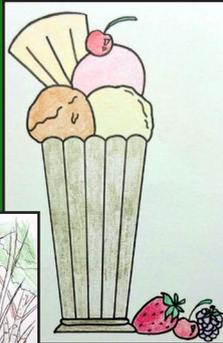


Lucy (14)



Seini (11)

Ellie (16)



Ellie (16)



Noah (10)

India (13)



oo poorly to do it herself



Both
Fabian (12)
Felix (17) and
Francis (14)



Noah (10)



Daniel (13)

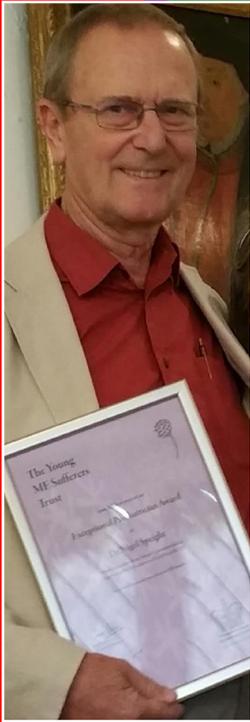




Ingatestone Hall Afternoon Tea And Presentations

Another happy summer event. Parents and young people with ME, Tymes Trust Trustees, volunteers and guests including Lady Carter with Mrs Jill Need, wife of the Rector of Stock, Kyoko and Dhruv Patel, CEO of Nisai Learning, and Gordon Radley, formerly of

Sky News, all gathered at the ancestral home of Lord Petre, the Queen's Lord Lieutenant of Essex. Lord Petre had presented the Trust with the Queen's Award for Voluntary Service in 2010.



Dr Nigel Speight

Executive Director Jane Colby gave Dr Nigel Speight, attending with wife Heather, a Tymes Trust Exceptional Paediatrician Award and a statue of Asclepius, Greek god of healing medicine in classical times. Jane joked to much laughter: "Everyone knows that doctors think they're gods!"



Asclepius

Our Scottish Officer Lesley Scott received flowers for her outstanding work north of the border. She recently held an evidence gathering session for parents, which revealed that family services are being shunned as parents cannot trust their data not to be illegally shared due to the Scottish system. Their evidence was then presented to the Scottish Parliament.



Lord Petre

We also displayed a large copy of the advertisement we placed as part of our GP awareness work, in a journal that is circulated to all GPs, promoting our GP's leaflet.





Jane and Lesley

Finally, all the young people attending (including Fabian) received a colourful set of fine liners, and those who had been ill on the day were also sent a pack. A summer's day to remember.



Jane and Alexandra, a longstanding Tymes Trust member



Would you like some flyers for our GP leaflet?

We are delighted that following representations by Tymes Trust, Dr Speight and others, NICE has agreed to produce a new ME Guideline. Prof Mark Baker of NICE has asked Jane to attend a New Year workshop. Read our submission to NICE at www.tymestrust.org.





It's Christmas!!

Jane says: "Thank you, Yvette. Yes, we've all been good... if you have a hotline to Santa please let him know!" Yvette was the youngest presenter on Blue Peter aged just 17 and is famed for her long running Most Haunted TV show with husband Karl Beattie.



And Seb (helping us decorate)

says: "I saved this photo of Fabian's 9-foot Christmas Tree from last year, just to bring it to you now! Looks as if the whole McDonald family sprinkled it with shiny shimmering baubles and sparkling tinsel. Oh I am so eloquent today."



Why not tweet your own tree to us @tymestrust?



Huge thanks for all the kind donations to fund our work for children and families. Congratulations to Hannah Carling and Matthew Goodchild (right): Hannah ran the Pershore Plum 10K and her church (Godfirst) held a fundraiser, total £605; Matthew ran the St. Albans Half Marathon, total £1,079.



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Advice Line 0845 003 9002
Joint Parent and Child membership available
Register at www.tymestrust.org
Registered Charity 1080985

