



TEACHER PAUL WILLSHIRE RECEIVES HIS YOUNG HEARTS AWARD CERTIFICATE FROM AMY DAVIS



I regularly hear of children with ME who are poorly treated by 'the system' and whose many needs are misunderstood. Advising families who encounter such obstacles is a large part of the Trust's work. It is therefore especially rewarding to be able to give public recognition to professionals who go out of their way to understand and help these young people, whose illness is, as the government Department for Education rightly says, 'not their fault'.

In honour of the Trust's Young Hearts Day 29 November, member Amy Davis has presented her teacher Paul Willshire with a Young Hearts Award Certificate. This year's other recipients include GP Dr K Riddle and Danny Elliott, coach at Newport County AFC.

You may recall that Young Hearts Day began when Terry Waite CBE, former Special Envoy to the Archbishop of Canterbury, launched our book of young people's poems at Warwick Castle in 2004. Since then we like to light a candle on the day to remember young people with ME everywhere, particularly those who are severely ill and easily forgotten by the outside world. We also run a Twitter Q&A on the day. All are things you can do from your home, so no-one need feel left out.

This year's Tymes Tidings also recognises our wonderful volunteers who give so much of their time.

Kindest regards

A handwritten signature in black ink that reads 'Keith Harley'.

Keith Harley  
Chair of Trustees



FLYERS AVAILABLE

## ME – THE NEW PLAGUE 2: RECLAIMING THE PATIENT'S VOICE

Have you been reading my new book? Released free of charge at [www.methenewplague.net](http://www.methenewplague.net)

In the original *ME – The New Plague 1* detailed evidence for the viral causation of ME, and in particular the link with poliomyelitis, a terrible disease that has again broken out in other parts of the world. In this sequel which will, on completion, be available as a printed volume, I am spotlighting the scandal of how ME patients have been ignored and

their experience belittled. And I again address, and update, the link with polio family viruses.

Mary Schweitzer PhD in America agrees with me that: 'From the standpoint of the history of ME I would think the most exciting work is John Chia's, because he has brought things back to Coxsackie B, a polio-family virus, which was where the biomedical research in the UK broke off after the Holmes Committee met in 1988 and gave the medical world the term CFS with which to bludgeon hapless patients.' As we know, the artificial invention of 'Chronic Fatigue Syndrome' was a disaster. Classic ME has been sucked in under its umbrella, mixed with other pathologies. The Trust has campaigned for years to have ME once again recognised in its own right. We have great support in this, and we believe we are succeeding.

Jane Colby  
Tymes Trust Executive Director



## THE COUNTESS OF MAR, TYMES TRUST PATRON

Lords Committee stage, Day 6, Children and Families Bill, from Hansard: 'My Lords, I shall speak to my amendments [...] I first became interested in virtual education in 2004, when the Young ME Sufferers Trust, or Tymes Trust, developed an alliance with Nisai Virtual Academy Ltd, also known as Nisai

Learning. Together, they developed an educational programme for young people who were too ill to attend school or who could attend only intermittently and who, as a result, were missing out on large chunks of their education. At a function in the House last year the noble Lord, Lord Clement-Jones, founder-patron of the Tymes Trust, said: "No wonder students with ME

# THE TYMES TRUST TEAM

We thought you'd like to put faces to the Trust's amazing volunteers. We'll bring you some others next time.

One of our mums writes: 'In the last few weeks since I contacted Tymes Trust we have received more support and understanding than our family received in total in the last ten months since she first became ill.'



## 'PERU'SING THE AMAZON RIVER (SORRY!)

Mark Colby, our web designer and

technical wizard, is Systems Designer at Life Racing. Autosport fans see [www.liferacing.com](http://www.liferacing.com)

for the music department. Parklands was buzzing today.' The concert raised £500 for the Trust. Amy gave a presentation on ME to her class and Assemblies were held each morning for a week 'so at least 900 young people and staff now have an awareness of ME.'



Many thanks to Parklands School for its magnificent effort to raise awareness of ME throughout the school and among parents. Sue Davis, mum of Amy (see cover) writes: 'Last night's concert was fantastic - the best yet

Thanks also to Hereward House School for a further kind donation of £350. They have been very supportive of the Trust's work.

If your school would like to raise awareness or fund-raise, the Trust can supply posters and leaflets to help.

find concentration so difficult. When a student makes an effort, oxygen levels in the brain can fall instead of rising to cope with demand. Obviously, it can be next to impossible to study effectively after struggling into school."

'He finished by saying that, "students can be thought lazy, or just awkward when they are doing their best. Often

staff do not realise why the student either can't get to school at all or can't concentrate on their work when they get there".'

The Countess's amendments are intended to insert virtual education into many clauses of the Bill.



## RUSSELL'S ROUNDUP

It's that time of year again. 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.



## QUESTION TIME

On behalf of MESH and Plymouth & District CFS/ME Group,

thank you to Tymes Trust for your extremely valuable input at the MEA Question Time event in Liskeard, Cornwall.



## RICHMOND AND KINGSTON ME GROUP

Jane, thank you so much

for coming all this way to Surrey to speak to us, we really appreciate it.



## TOM KINDLON

Chair of the Irish ME/CFS Association, a Partner Group to Tymes Trust, Tom is author of a superb peer reviewed paper: *Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*. Free online in the Bulletin of the IACFS/ME. [bit.ly/tkharms](http://bit.ly/tkharms)

## CLARE'S VIRTUAL TRIP

Fed up feeling ill? Grab your virtual passport and get ready to be whisked away on a fabulous virtual adventure. Set sail aboard your own private, luxury yacht. Relax in your five star accommodation as you explore the vast ocean. Receive your exclusive, free virtual day trip audio and e-magazine at [clairewade.com/freetrip.html](http://clairewade.com/freetrip.html)

## BELLA HOARE'S ME SPACE

Bella now has a closed Facebook group called ME Space. 'They request to join and I accept and welcome them!'

## NANCY BLAKE

Nancy's excellent Guest Editorial for *nhsManagers A Radical Care Pathway for ME/CFS* states: The expensive centres which have been set up, requiring patients to attend in order to engage in extra exertion (just getting to a hospital appointment is enough to wipe out an ME/CFS patient for days) should be replaced by [...] domiciliary services. Apart from encouragement to keep on resting, and encouragement to family members to appreciate that this is needed, the patient should be left alone, allowed plenty of time to get better. Under this regime, gradual improvement is to be expected (school-age children should be provided with home education until a gradual return to school becomes a possibility). [bit.ly/nhsmepath](http://bit.ly/nhsmepath)



## EMMA MANNINGS WITH CHARLEY AND JORJA

I am delighted to enclose a cheque from the Mannings family. We raised £177 from donations of £1 to wear onesies or Pjs to school and a cake sale and we added the rest as a thank you. The Tymes Trust has been my rock. They gave me strength and information to turn a negative situation into a much brighter future for my youngest daughter who has ME. With their help I have worked with the school to raise awareness.



## SIAN'S CAKES

Dawn Jones kindly donated £62.70: 'Rhys' mum Sian is a fantastic cake decorator, making cakes to raise money for good causes. She has been on courses with Eddie Spence who has decorated cakes for the Queen.' Rhys Jones nominated Danny Elliott, coach at Newport County AFC, for a Young Hearts Award: 'I was in their under 16 team when I was diagnosed with ME/CFS and he has supported me all the way through. He is always there to talk to and understand. I have managed to pass an FAWV course for goalkeeper coaching. Thank you

also for your help with my English Exam.' Dawn says: 'Rhys went to watch them play and Dan and Glyn (head of the Academy) let him sit on the bench with the rest of the subs.'

## OMEGA ME GROUP

OMEGA ME Group, Oxfordshire Partner Group to Tymes Trust, are seeking local parents' views on children's ME services. Questionnaire at [omega.webform.com](http://omega.webform.com)



## JEN FLYNN AT UNI

Thank you Jen for raising another £1000. Jen is a Young Officer of the Trust and attended our latest House of Lords event. Could you be a TT Young Officer?



**WHERE DO YOU THINK I'M HIDING?**

My friends and relations came for a sleepover and we all played

hide'n'seek. Can you copy the picture and draw me somewhere in it? Send it to me for an Art Prize.

I'm still collecting your poetry. Don't forget! My folder isn't nearly big enough. Why not write to me about what it's like to have Christmas with ME, and I'll put it into a poem for you. I'd be honoured.



This time my Spread is big on photography. When Suzanne from

Canada sent £200 for our work, we displayed her pretty 'thanks' card and Mr Harley took this photo. More photos please.

**OUR YOUNG HEARTS DAY CANDLE**

Remembering children with ME everywhere.



**LIFE THROUGH MY LENS**

Looking through my camera lens altering the focus  
Trying to get a good clear shot keeping it all in the frame.

Photography keeps me occupied My life otherwise on hold. It makes me happy, lets me see the world in different perspective.

Looking at my pictures, happy with the shot. Pondering on why ME – why now – why? No answers, sadly, come to me. So try to just deal with it day by day.

I have hope – I want to be a photographer, To go to College and learn how. To have my own studio and meet people, To live, to laugh, to cherish life and love.

*Verses from Tasha Mawer when aged 14.*



**PLEASE GIVE ME A HOME**

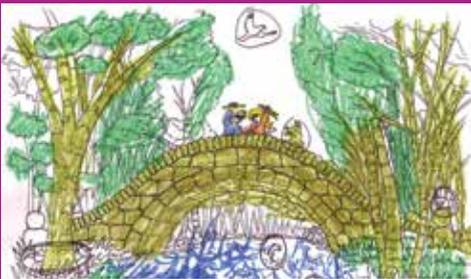
**MR HARLEY'S BABY SNOWMEN**

Mr Harley has found more baby snowmen! So his Annual Gift of Bears is a Gift of Snowmen! Small and cuddly, they can go in your pocket – and they won't melt. Let us know quickly if you'd like one as a special present. They're getting really excited.

# MY ART GALLERY



We hope you enjoyed colouring Gregory's Poohsticks. Here are some of your colourings. (Needless to say, I am a brilliant artist myself. And poet. In case I forget to say it.) Here I am choosing a pencil.



JORJA MANNINGS (AGE 6)



FABIAN MCDONALD (AGE 8)

Fabian's mum writes: 'This reminds Frances, Felix and Fabian of playing Poohsticks in the park. They are all too ill to get there. Happy memories.'



BEN BY MUM DEBBIE: 'MY ME WARRIOR'



I love these pics by Tymes Trust Young Photographer Lynn Connolly. She spotted these rare breeds at Mellon Fun Farm, Omagh and two doves in her own garden. How did she manage to get so close?

Would you like to be one of our Young Photographers? Send me a photo for my Art Gallery. As Tymes Trust's resident spider, I have my own email address! Email selfies and other photos to [seb@tymestrust.org](mailto:seb@tymestrust.org)

Greg, Anita and Isabella say: 'Can you spot the 11 hidden Candy Canes? Everyone can help find them. Tell us how you did.' The Contact Us form is at [www.tymestrust.org](http://www.tymestrust.org)

**The Young ME Sufferers Trust**

## COLOUR GREGORY'S CHRISTMAS



Your Name, Address & Age

Send your colouring to us for a prize. Include a stamp if you'd like it returned, and don't forget to add your name and address!

Send to: Gregory's Christmas, Tymes Trust,  
PO Box 4347, Stock, Essex, CM4 9TE.