

The Young ME Sufferers Trust

2009-3

£3-95

Vision

for young people, families and professionals

HOUSE OF LORDS 2010

Tymes Trust / Nisai Virtual Academy Awards
Your Display : 'How ME Affects Me'

REVIEW OF 2009

Judicial Review of NICE Guideline
Royal Society of Medicine Conference
ME and Viruses - Should we be worried?

THE BRIEF

Jane Colby's complete Witness Statement
for the Judicial Review of the NICE Guideline

View in full colour at www.tymestrust.org

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THE YOUNG ME SUFFERERS TRUST

Registered Charity Number 1080985

Founder Patron	Lord Clement-Jones
Patrons	Earl Howe Shirley Conran The Countess of Mar Princess Helena Moutafian Terry Waite Barbara Windsor
Friends Patron	Lady Elizabeth Anson
Chair of Trustees	Keith Harley
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Our Patrons



Lord Clement-Jones CBE



Earl Howe



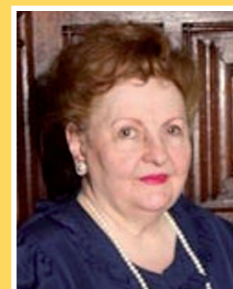
Shirley Conran OBE



Lady Elizabeth Anson



The Countess of Mar



Princess Helena Moutafian MBE



Terry Waite CBE



Barbara Windsor MBE

Vision - The Project

The Trust comes of age in 2010! We are the longest running service for children and young people with ME. As we approach our 21st year, I thought you would like a summary of what we provide, what it costs and what makes us unique.

Philanthropy

The Trust runs entirely on the well-respected, time-honoured principle of philanthropy and volunteering. This includes everyone to whom you speak when you contact or email us. No-one at the Trust is paid for their time and commitment. Endorsements have come from many prominent figures, including former Prime Minister Tony Blair, and David Cameron MP, Leader of Her Majesty's Opposition. Their comments can be read on our website.

We have 35 volunteers, including a full-time Executive Director, an Advice Line Coordinator, an Advice Line Team and a Professionals Referral Service covering the professions of Education, Social Services, General Practice, Paediatrics, Psychiatry, Public Examinations, Pharmacy, Educational Psychology and Welfare Rights.

Our website, designed as an ME-friendly resource, is run by a professional software engineer and carries magazines, reports and publications that you can download free of charge. It is regularly archived by the Wellcome Trust in the national interest.

The Trust also has Partner Groups throughout and beyond the UK whose work we support, a partnership with the Nisai Virtual Academy, and a Trustcard scheme to protect children's health in schools.

And of course we take a national role in campaigning.

Efficiency

We nevertheless run a very tight ship when it comes to finance.

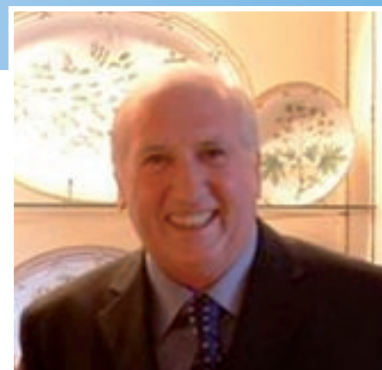
During the last financial year, we managed to provide all our services, including all costs for administration, telephone, post, travel to the Houses of Parliament and other essential venues, plus your birthday and Christmas cards, individual information packs, services to Partner Groups, printing of *Vision*, *MiniVision*, *The Quick Tour* and all those other many costs that come with running a charity, for the total sum of £10,134.

Those of you who run businesses or manage finances will know what an achievement this is. It certainly couldn't be done without loyal and regular work by our Team who give their time in so many ways. I would like to take this opportunity to express my appreciation of their commitment to providing a professional, top quality service.

Independence

I realise, of course, that by drawing attention to our cost-effectiveness we might give the impression that we don't need your fundraising efforts. Far from it!

We receive no government grants; indeed we do not seek them as, in the words of Libby Purves, such grants come with implications. As she aptly put it in *The Times* (23rd December 2008) 'Government grants also act as a secret gag, preventing harsh plain-speaking against bad policies by those who know their stuff'. The Centre for Policy Studies has criticised state funding for charities for the same reason.



Keith Harley

We rely on donations and fundraising efforts by you, so we can maintain everything upon which you depend, mount special projects when funds permit, and preserve our vital independence. I hope we have been able to help you personally this year.

Keith Harley
Chair of Trustees

Thank you Shirley

Trust Patron Shirley Conran OBE has kindly sent us an amazing parcel of vouchers. If you would like to win one of these special prizes, full details are on page 13.



Monthly News Emails

Do you have an email address? Are you getting our alerts emails? If not, type your address into the box at www.tymestrust.org. Previous alerts can be read there too.

Mark Colby says: *We created perhaps the first ever ME resources website nearly 15 years ago. We've always seen the web as a powerful, cost-efficient way to get information to as many people as possible. We try to keep our site simple and focussed so you can easily find what you need, and the Alerts emails are a natural extension of that.*



House of Lords 2010

your contributions for display on ME Awareness Day



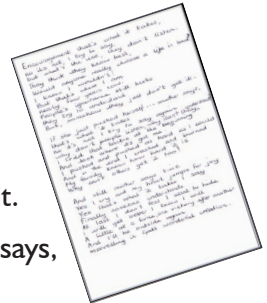
The partnership between The Young ME Sufferers Trust and the Nisai Virtual Academy, which I launched in 2004, has been successful beyond what anyone could have hoped for. I greatly look forward to hosting the next Learning Commitment Awards on May 12th 2010. It is also heartening to see the members of The Young ME Sufferers Trust producing such powerful artwork and poetry for display on the day. I am seriously impressed!

Lord Clement-Jones CBE
Founder Patron

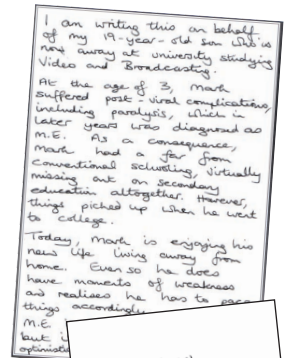
We asked if you could manage to send in your contributions for our House of Lords display in time for Young Hearts Day 2009. Why? Because we have spent Young Hearts Day thinking of you all and arranging these pages. But you can still send us your contribution for the display. Deadline is the end of April 2010. To get your display frame, go to www.tymestrust.org/tymesmagazine.htm and download it, or just write in and ask us for one. If you aren't able to write, someone else can write it out for you, or just email us your contribution, as Chloe did, using the Contact Us form at www.tymestrust.org and we'll print it out.



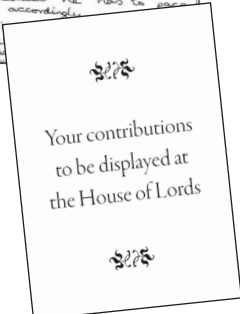
Encouragement, that's what it takes,
No it's not, I try to say,
but what's the use, they don't listen.
They think they know best,
Would anyone really choose a life in bed?
I know I wouldn't!
But that's where I am
nearly four years now.
People's ignorance still hurts
they try to understand
But, somehow they just don't get it.



If she just pushed herself ... another says,
that's what it takes
No it's not, I try to say again
why don't people listen, why don't they understand?
I tried that tactic at the beginning
And look where it's got me.
I pushed and pushed as hard as I could
And in the end I crashed and burned
My family know how hard it is
Why can't others get it too?



And still another says time
Yes, I cry, and my heart jumps for joy
Yes, that's what it takes I say
Finally someone understands
At last I don't feel I want to hide
I will get better, I know I will
A little at a time, one victory after another
And I'll be outside again
Marvelling in God's wonderful creation.



Hannah Carling (22)

Words - Helen Burnley (19)

therapy' even when I'm most ill. The quote at the bottom is from a poem I wrote recently. I have enjoyed being more creative lately by making cards and painting

by numbers. They require quite a lot of energy and I need to intersperse rests but I really feel I have achieved something when I complete them.

I think it is great that you involve members with tasks such as the House of Lords display and easy, free competitions as well as including latest research findings in your magazine.

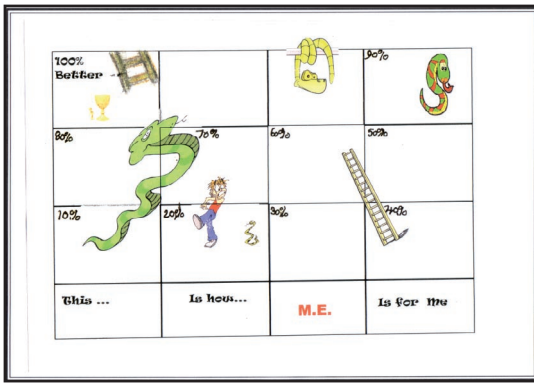
Best wishes to everyone
Sophie Baggs (24)
and Pluto and Gray (cats!)



Thank you for inviting me and other members of Tymes Trust to contribute towards the display for the House of Lords. I have taken this opportunity to express my creativity

and tried to express my feelings towards the illness and show how it affects my life as clearly, truthfully and succinctly as I could.

In the A5 frame I presented a picture of me and my two cats who often keep me company and provide comfort and 'furry



Can you imagine waking up not able to move, not even a finger,
 Wiggle a toe, move an arm or a leg?
 Can you imagine lying there not able to move, but vomiting,
 Being too scared to breathe, choking till your parents roll you over?
 Can you imagine being so ill you can hear the voices of your parents but not know who they are?
 Or hear English but not understand a single word?
 Can you imagine going months on end without seeing anyone outside the family,
 Not a single soul, not even a milkman or passerby?
 Can you imagine being in so much pain that you just want to give up,
 Feeling like there are thousands of hot pins sticking in you?
 Can you imagine going years and years with a continuous migraine,
 Not easing for a minute or a second of your life?
 Can you imagine going over a year without sitting up or propped up,
 Feeling so dizzy that you can't see straight?
 Can you imagine feeling like you are moving, falling over backwards,
 And at the same time rotating you sideways all the time?
 Can you imagine going 6 months without going downstairs in your own house,
 Not seeing the living room, kitchen, garage, or garden?
 Can you imagine life like this?
 I don't need to imagine after all, I live like this every single day.
 Still think ME is just about feeling tired?

Vikki George (25)

This is how ME is for me...
Katherine Perry (26)

ITS CHRISTMAS!

Well almost; but my son Max wakes me up every day asking whether Father Christmas is stuck in the chimney or whether the elves have left any sweets for him.

I have no idea where he's picked that up from, we are an entirely Elf-free household, but however bleary eyed and cross I am at first (well...sometimes it's four in the morning!) I can't help but eventually be won round by his imagination and wonder about Christmas and all that goes with it.

I really hope that this Christmas all of us will be able to remember how exciting and magical Christmas can be, and however many ups and downs the past year may have thrown at us, that we'll be able to share a smile and a cuddle with those we love at Christmas, and face the new year with a new sense of strength and determination and peace.

**Happy Christmas!
 Burn and Family (and the elves)**



Burn Gorman

(Torchwood, Bleak House, Wuthering Heights, and above as Bill Sykes in Oliver Twist at the Royal Court Theatre, Drury Lane) was a guest at our last Learning Commitment Awards



Earl Howe with Dhruv Patel, CEO, Nisai Virtual Academy

'Well done to our ME students, who have obtained such spectacular results working from home.'

Read how the Tymes Trust/Nisai Education partnership can help you: www.tymestrust.org/pdfs/succeedingwithme.pdf.

I am writing this on behalf of my 19-year-old son who is now away at university studying Video and Broadcasting.

At the age of 3, Mark suffered post-viral complications, including paralysis, which in later years was diagnosed as ME.

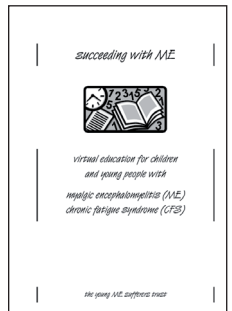
As a consequence, Mark had a far from conventional schooling, virtually missing out on Secondary education altogether. However, things picked up when he went to college.

Today, Mark is enjoying his new

life living away from home. Even so he does have moments of weakness and realises he has to pace things accordingly.

ME is a devastating illness, but it is important to remain optimistic.

**On behalf of
 Mark Lever**





friends
school
family
ME/CFS

I will get better though
I feel like I'm letting everyone down

Cheryll Neyt (22)

where I was taught pacing techniques.

Four years on I still have to rest regularly to keep control of the fatigue and other symptoms as much as possible. I still miss being able to do things I could as a healthy person, but try to remain positive about the things I can do.

I have managed to learn to drive which has given me some freedom. I am presently working towards achieving GCSE Maths and English. I will need these qualifications to be a support tutor; a job which I hope I could manage due to the flexible working hours.

Hope that one day I will be well enough to study or teach full time, play my brass instruments, cycle again rather than driving everywhere and generally be able to live life full time not part time.

William Robinson (20)

I lay there day and night, dreaming a dreamless dream.
I was so weak, and nobody knew why, not even me.
When I went to school I could only stay for a short time,
As a result of this I missed out on an important thing; friends,
they did not understand, it was not their fault.
But my special friend was simply the best;
He knew me inside out and somehow understood all that was going on.
He has a muzzle as soft as a pillow; his neck is as supple as willow,
a forelock as warm as toast, legs so strong he could gallop to the coast,
His heart so full of love much warmer than any glove.
Of course he's a horse, my best friend.

Anna-May Furness (14)



Four years ago the trouble all started with a virus which I didn't recover from. I was diagnosed with ME.

I was then referred to an ME clinic

The Battle Within M.E

Everything had seemed so normal.
The day before the nightmare began
I was fine.

A happy wild child,
More energy than a lithium battery
Running about, laughing, 100%
I went to bed as normal
Running over the last days events
In my mind.
Feeling the cat lying near my feet
It was the last time I felt well.

Then disaster struck!
A bomb smashed my hopes and dreams
To smithereens
Over night.
M.E had attacked.

Slunk into my house, chosen its latest victim
And struck.
I lay in bed. Engulfed in a blanket of fear.

Struggling with fever.
My legs felt like molten rock
Was slowly being poured into them.
My head was being crushed in a vice.
M.E had hold of me
And it wasn't letting go.

I was in M.E's clutches.
In a cage of barbed wire.
A demon was now in control.

My hopes of adrenaline jobs
Gone.
Sailing around the world.
Yeah right.
My battery was empty.

Age eight and I lost my childhood.
It was stolen cruelly by M.E
No more running and skipping
Laughing and playing.
My life was stolen.

Even now the battle rages on.
But I am slowly regaining control.
M.E has reigned control for too long
And I have the ring of keys to my cage.
It's just a matter of finding the right key

And then.
I will be free.
And then.
I will have beaten M.E

Chloe N Halstead

what you think

Hello, I received my first issue of *Vision* yesterday, but had an especially bad day and couldn't get round to opening it until today. I just wanted to thank you for sending me it, it feels so amazing knowing other people suffer with this too, and have done such amazing things with their lives. It's like a whole new support group has just opened up for me. It really made my day reading it, and I wanted to let you know how amazing it is (even though it took two hours to write this!)

Kati Blake

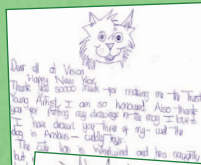


Thank you so much for making me the Trust Young Artist. I am so honoured.

Also thank you for putting my drawings in the mag. I love it.

I have drawn you three of my

cuddly toys (well, the dog is my sister Amber's!) The cute lion is Whirlwind and he's naughty but is very soft underneath. The cat is Snowflake, leader of the group, who causes havoc. (He also calls himself Spitfire. No-one knows his real name.) And the floppy dog is Hurricane. They're real trouble-makers.



Enclosed: a donation towards the work of the Trust.

We can't reveal this generous benefactor's name but we would like to thank you for your support.



Love, Chloe Halstead

Chloe has been quite unwell again this year. We'd like to send her and her family all our love.

Just a small donation to thank you for coming to my aid so promptly a few weeks ago. Your support and valuable advice are much appreciated.

Best wishes, Rosie



It's so hard to know what to do when doctors are telling your child to make more effort to exercise etc and taking their advice seems to make everything worse!! Rachel

Our Professionals Referral Service can put you in touch with doctors on our panel who will discuss problems like this.

The information specific to ME and swine flu was very helpful.

Thank You to you and your other volunteers for providing such a great support. Whenever the responsibilities seem too much and confusing it has been good to know someone else is out there and can help put things in perspective. As a parent it is hard to accept we don't have a magic wand and can't make everything right and we don't have all the answers. However due to websites like yours we can continue to keep finding out more. With many thanks not just for this occasion but for others in the past when you've been able to help. It really is good to speak to someone who KNOWS what it feels like to be a parent of a child with such a confusing and frustrating illness.

Kind regards, Ursula Ward

Thank you for my calendar.

I love cute animals. I also love that it is

personalised. Elizabeth Bell

You can win a personalised calendar. See Things 4 U 2 Do.



Whenever you write in or email us, don't forget to say if you'd like to be quoted in Vision. It means a lot to know what you have found helpful - and it also helps us to plan. Send us a photo as well if you can!

WHAT HAVE YOU BEEN DOING?

From a home tutor: I am writing to you as a tutor for children and young people with ME.

My husband also suffers with it, so I have become a 'sort of expert' in this area.

As a home tutor I found I was often the only person seeing the student other

than their family! I tried to help the parents too, encouraging them and helping when they were down and frustrated.

Some of my problems were caused by ignorance - it's astounding how many staff in schools and other educational establishments are still ignorant or dismissive of ME. Every one of my students has been hurt one way or another by this!

One concern is the lack of training especially for home

tutors. I have often 'helped' tutors over the phone but have been appalled at the stories and situations, described to me by parents, of their experiences with 'well-meaning' tutors who have done the 'wrong things'.

However the main problem is money or lack of it. We are treated as supply teachers, given an hourly rate, and are only paid for the time with the child. As you are well aware, ME students are often unwell; one of my pupils was too unwell for tuition for a whole term. I had a number of pupils allocated to me at five hours a week

but most could not manage the full amount. It sometimes worked out that

Jasmin has just received her certificates from Nisai Virtual Academy, one for Science Student of the year and also a Certificate of Merit for excellent effort in completion of science assignments, plus a £50 voucher. We are so thrilled for her as the last time she did any sort of science was 4 years ago!

I just wanted to say that all the staff at NVA are really wonderful and caring people. All



of her teachers are smashing and give Jasmin so much encouragement which is what she needs after missing 3 and a half years of secondary education. Jasmin's school let her down so badly when she really needed them and we had several fights with them. They are now arguing because they have to pay for her to sit ONE GCSE!

As for the bedroom being a quiet place, forget it! Jasmin does everything from her bed and so she should. We had months and months of having

the curtains drawn all the time and tip toeing around as she was so noise and light sensitive it made her cry with pain. That was when she was at her worst and paralysed, so now it's curtains open, laughing, painting, card making, in fact anything being done from bed is a massive improvement to what she has had.

Thank you once again from the bottom of our hearts for giving Jasmin the opportunity of a future. She is now ploughing her way through university prospectuses which she wouldn't have considered doing just a few months ago.

Jo and Jasmin Wakeford

I have had ME for 10 years now; it's only in the last 18 months I've been well enough to live life day to day. Finally now I'm doing really well in life. I'm in year 10 and am doing my GCSEs, having already done an early extra GCSE Geology in year 9 and getting an A which was a real achievement for me because I have missed so much education (2 years!) and the best thing is I m now strong enough to be able to ride my pony nearly every day properly!

It just goes to show that if you believe in yourself and take things step by step whether that be school, hobbies, or simply being out and about enjoying yourself you can get anywhere. Just sometimes it takes a little longer because you have to take a rest along the journey of life, but that's OK. You have to remember, little things make much bigger things.

Anna-May Furness, 14 years old

David got a 1st class hon's in architecture from Liverpool Uni this summer - with lots of pacing! The Uni Disability Support people were brilliant. Please tell people NOT to give up. Val



Meet The Team



Joy Birdsey
Bsc Hons
Advice Line Team

Joy has given this evidence (in greater detail) to the APPG Inquiry on NHS services for ME patients.

I am a fully qualified psychologist and have taught psychology. In no way do I believe that ME is a psychosomatic illness. Robust biological studies refute this model.

I have had ME myself since 1994 so I tried my local Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET) clinics.

CBT should be personal; the facilitator should know the patient, so as to help them learn to cope with their disease, find their goals and help facilitate them. Most importantly, they should know about personal circumstances. This can't be done in a group, yet that was what we got.

I know how to pace myself and adjust my lifestyle to compensate for

ME. I drove to the centre but was not expecting a trek through the hospital to the appointed room! On arrival, I was in pain, exhausted, and 'out of it.' In group sessions, some are too shy to share, some dominate. It's ineffectual as people's needs are not met. So they don't come again and fall through the net, which is what happened. We were 15; by the last session there were only 5 of us.

I asked about pain control, but there was none. The monthly sessions entailed forms to be filled in at home, but I would be ill for over a week with pain and exhaustion. When I am ill I can't write a letter let alone fill in what I am doing! I haven't the energy to even find a pen. But I attended for a year. We were left in utter dismay. We had seen no consultants, nothing was done for us medically, just flip charts, forms, asking had we achieved any of our goals, and talks on meditation. We were given a CD on relaxation.

The GET sessions did not work either. The drop out rate was 75%. We were asked to increase our

walking by 10% each day. At that rate, I would be walking the UK in a year. During a session a man collapsed. We were all afraid for him because most of us knew that a person collapsing with ME needs to be laid down and cared for. As he fell forward, the group leader told us to leave him; he would be ok. They just left him there. He could have collapsed for serious reasons and I felt he should have been investigated, there and then. Later, I saw this poor man walking very slowly with his wife to his car.

My conclusion was that the GET advice was dangerous and that the 13 sessions of CBT were a waste of NHS money as they appeared to have had no medical benefit at all. Data collection was biased as we were collectively asked by the therapist how we rated the sessions. To collect data of this nature we should have been asked by an independent person, so everyone felt free to answer honestly.

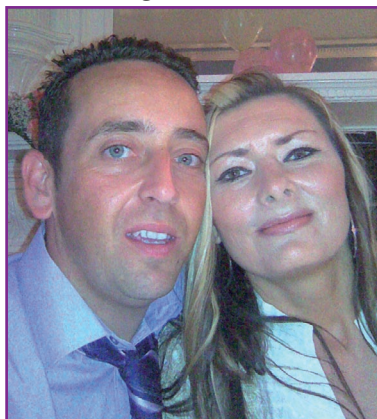
Joy needs an operation and will not be on the Line for a while. We all wish her well.

Marie Cother
Advice Line Team

Marie is training to be a nurse. She volunteered for the Advice Line after

we helped resolve the case when social services started investigating why her daughter was not at school.

Marie with husband Mark and her daughters Leanne, Jade and Amy-Leigh



Marie wrote: Absolutely fabulous news, the case is closed! Thanks again for literally saving our lives (well that's how it feels to us!) If you could do with another ear on the Advice Line, I would like to help. I can only repeat that if it wasn't for the Trust we'd be in a real mess! I'd be very happy to give something back.

All our Advice Line Team have full information about ME.

Phone 0845 003 9002



Jennie Whitlock
Trustee

Hallo everyone!
I've been stuck in a big stiff

collar for months. Someone drove into my car. So I thought I'd let you all know why I haven't been able to write to so many of you recently; the accident broke my neck and damaged my arm. Thank you to everyone who found out and sent me Get Well cards!

Fundraising - Many Thanks!



Katie Durben
Friends
Coordinator

Ways you can help

1) One of the easiest things you can do is to go to the Everyclick page that's been set up for the Trust by Jamie Hewitt (see right). It won't cost you a penny to use this search engine.

2) If you have artistic leanings or are interested in crafts, how about making something(s)? You could then either donate what you make to be given to the members, or sell what you make to raise funds. Also, if you could get friends to sponsor you for doing this you could raise funds this way at the same time.



Sponsorship forms can be printed off the website www.tymestrust.org.

David Hampton raised £75 running a Local Producers Market stall in aid of the Trust at Lawford C of E Primary School Fete on 4th July 2009



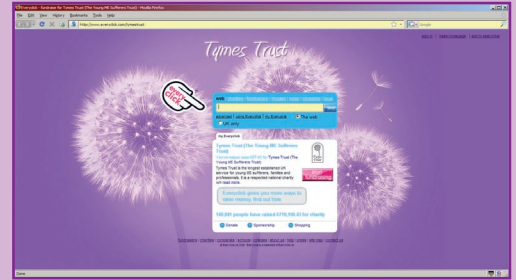
The winning recipe (by sales!) was smoked bacon, tomato and mustard, beating onion, cinnamon and mace by 3 sausages. Year 6's was a pork sausage coated in toffee fudge and hot chocolate - and no I didn't try to make it!
Yours, David Hampton

3) Hold coffee mornings or tea parties, as a one-off, or even better, do it regularly in aid of the Trust. We can supply leaflets for this. If you can manage a one-off, then maybe during this one you could also invite others from those who are present to hold them next time and maybe then they can do the same!

4) If you are given unwanted gifts, how about donating suitable, new gifts to the Trust to give to members?

Love Katie
x

Katie has raised £155 being sponsored to make gifts for our members. See Seb's page for her giraffe, and the front cover for a big picture of her tiger!



www.everyclick.com/tymestrust

Everyclick is a search engine that donates to charity each time you use it. The Trust has its very own Everyclick page designed by Jamie Hewitt where you can raise money for us just by clicking your mouse!

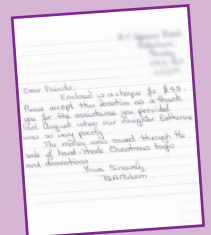


Jamie Hewitt with Jo-Anna Roberts, our Advice Line Team Coordinator

Barbara Milsom

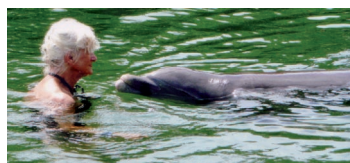
Please accept this donation of £48 as a thank you for the assistance you provided when our daughter Catherine was so very poorly.

The money was raised through the sale of hand-made Christmas toys and decorations.



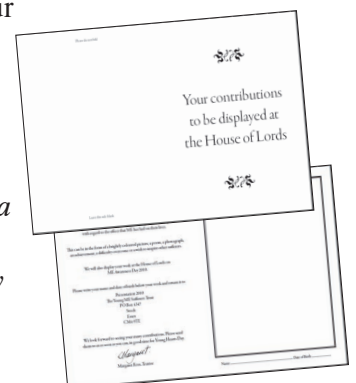
Margaret Ross Trustee

Margaret is in charge of the ME Awareness Day display at the House of Lords in 2010. She is also



preparing albums of your artwork and photos.

Please continue to send me your contributions for the display. You can send a picture, a poem, a photograph, news of an achievement, a difficulty overcome or a wish to inspire other sufferers.

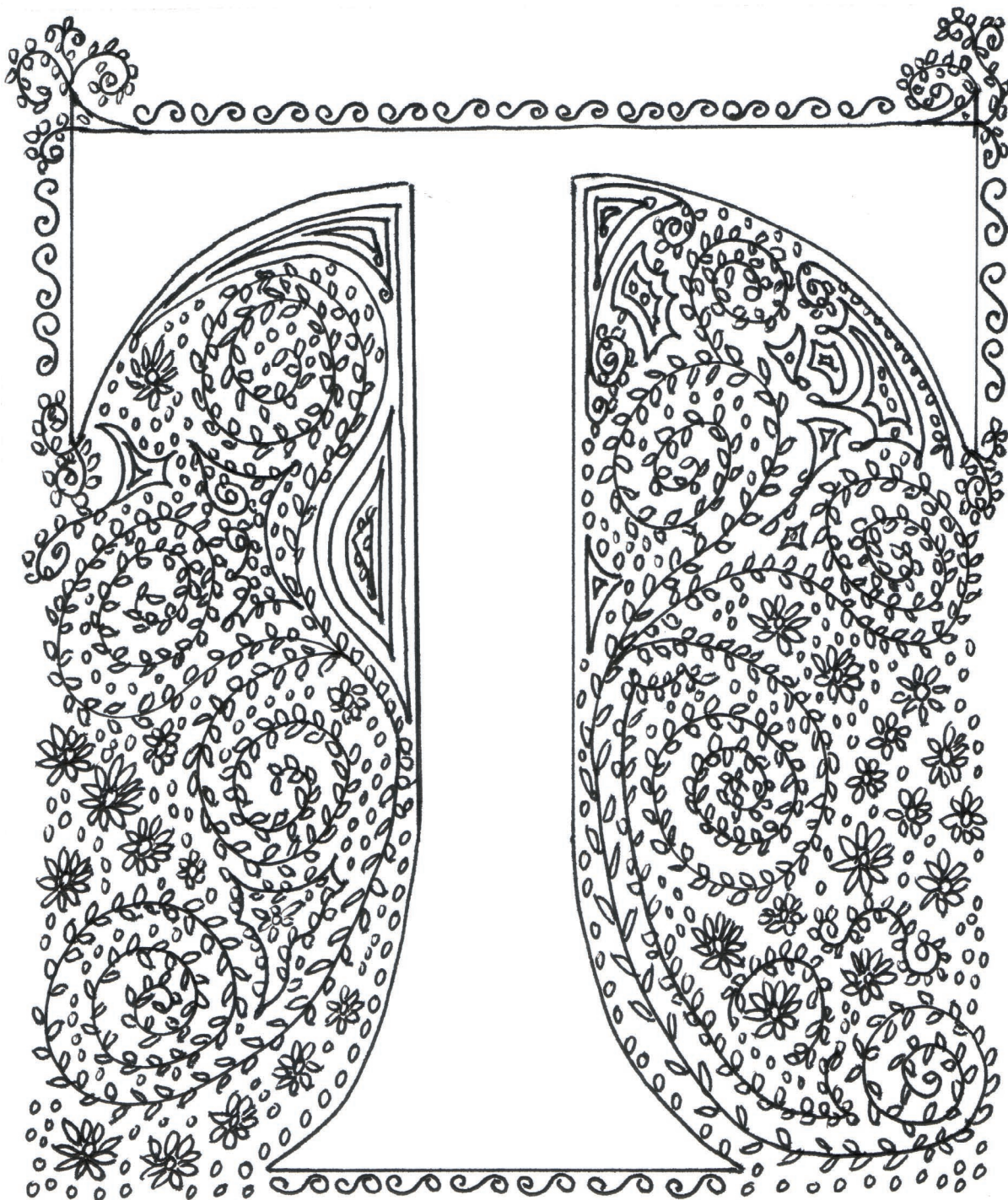




U 2 D o

Secret calligraphic illuminator decorates a medieval 'T' for Tymes Trust. Guess who?

Things 4



Centuries ago, long before the age of computer fonts, everything was written and decorated by hand. Ancient manuscripts are illuminated with flowers and leaves. We plan to display our name in the House of Lords with your other contributions. The more Ts the merrier!

We can't wait to see what colours you choose. Artwork can be therapeutic (make you feel better!) You could sit on the sofa or in bed (don't mess

up the duvet...) using pencils or felt pens. If you'd rather not cut up Vision, print this page from www.tymestrust.org/tymesmagazine.htm.

Name

Age

Address

STORY CHALLENGE!

SIX SHIRLEY CONRAN GIFT VOUCHERS TO BE WON



Using one of these story beginnings, invent the rest of the story. You have to get all the

words we've given you into the story! It can be as long or as short as you like.

You can play this game with

friends and family, you can make other challenges up. AND you can send your story to us and win a voucher!

An aeroplane was flying across the sea, when...

ENGINE
PILOT
DIVED
FAILED
RADIO
LANDED

There was once a circus clown who...

SAD
LAUGHED
TENT
HAPPY
PERFORMANCE
RING

I wasn't having a good day when...

ARRIVED
DOORSTEP
OPENED
PARCEL
ASTONISHED
STUCK

One night there was a dreadful storm and...

LIGHTNING
THUNDER
RAIN
FLASHED
BOOMED
PELTED

There was once a wizard who lived...

CAVE
BOOK
WICKED
ROCKS
SPELLS
MAGIC

In the middle of the night I woke up and saw...

EYES
WINDOW
DARK
LOOKING
SHINING
FRIGHTENED

SNOWY WINDOW CLINGS

We've still got some winter window clings if you would like some to decorate your room.

TEDDY AND FLOWER LABELS

LABELS

Message reads: We're supporting The Young ME Sufferers Trust.

Great to decorate envelopes.

£1.25 per sheet or 2 sheets for £2.



Ho Ho Ho

*Hey! cried the snowman
Can't you see?
There ain't no snowman
As happy as m - !*

*I was standing here
In my long striped s - - - -
When up came a guy
With a booming laugh.*

*Look! He's left me
A great new h - -
So I'm going to look
Pretty smart in that.*

*When everyone's gone
To their cosy b - -
I'll stamp around
In the snow instead.*

*I'll make big footprints
For all to s - -
And then I'll pretend
That it wasn't me!*

IS THIS OUR EASIEST EVER?!

Just find the missing rhymes. Count the dashes, one for each letter. We've even given you the first one.

First prize for first correct entry; a Tymes Trust Calendar for your room with your name on every page! Lots of other prizes. Draw us a picture to go with your entry and we'll publish it.



LISTENING LIBRARY

Don't forget that if you like reading but are too ill, we have negotiated free membership of the National Listening Library for members of the Trust.

**February 11
Judicial Review
of the National
Institute of Clinical Evidence
(NICE) Guideline on CFS/ME**

On February 11th and 12th the Trust's Chair of Trustees Keith Harley and Executive Director Jane



Colby attended the two day Judicial Review hearing in the Royal Courts of Justice. Although the patient challenge was lost, the

fall-out continues. In his Judgement, the Judge quoted Jane's definition of the term Chronic Fatigue Syndrome as an 'artificial construct' in the Trust's publication *ME - The Illness and Common Misconceptions* available at www.tymestrust.org/tymespublications.htm.

**Just Say No
The challenge to the NICE
Guideline was right, says
Lesley Scott, Tymes Trust
Advice Line**

The attempt in February at the Royal Courts of Justice in London to bring the NICE Guidelines to account should be applauded loudly and clearly for the bravery of those involved to stand against the shockingly inappropriate and harmful medical treatments that NICE advocate.

Although we are encouraged to stand up for our patient rights and told that refusing treatment we

consider ill-advised will not impact or affect future treatments, how many of us have agreed to go to psychologists, CBT or GET simply to be able to tick the box, to feel we have the doctors on-side?

We did; five and a half years ago our son had blood tests, brain scans and visits to child psychologists and physios. We mentally ticked off the boxes and followed all the advice in blind good faith. But when following all that advice results in your child relapsing and deteriorating before your eyes you begin to doubt; then that doubting leads to questioning and that was the best thing that we could ever have done.

Our questions led us to read all the information we could on ME; articles, research studies and publications one after the other, and this, coupled with the fact that we were with our son 24/7 meant that we saw and grew to understand the effects of this disease and indeed the effects of the medical profession's interventions far better than the doctors who saw him every three months to weigh and measure him and ask him the same questions they had asked him three months previously.

We took the decision to stop the hospital appointments which were clearly having such a detrimental effect on our son and had those moved to our local GP practice. At this point, our son was very unwell and it became clear that even the trip to the GP's was too much. Upon asking someone to come to the house to take the requisite weight and height data we were told that they do not do that on home visits and we would have to go there. The biggest journey our son was making at this time was from his bed to the sofa; we had reached our

crossroads. Eleanor Roosevelt said: 'You gain strength, courage and confidence by every experience in which you really stop to look fear in the face ... do the thing you think you cannot do.'

So we did. We decided that the doctors were not the best people to treat our son; we were.

He was left to sleep as much and as often as he needed; we took all the pressure and stress off him that we possibly could - no doctors appointments, no ferrying from this hospital department to another; we stopped all attempts to get him back into school in some form or another. We let him rest and heal in his own time and at his own pace. And we laughed. We tried to do something, anything each day that would make him happy; sometimes it was simply driving to the park and throwing a rugby ball at each other for fifteen minutes. But it made him happy.

Our son did not want to be ill; he has never thought of himself as a sick person. The tests that were done initially were good in so far as they ruled out other diseases and conditions; and it is important to have any new symptoms investigated. But day-to-day, week-by-week he was better out of it. By taking him out of the medical arena he was freed from the demoralising treadmill of pointless appointments and heartbreaking relapses; he set his own goals and made his own pace. As parents we are often all too quick to set aside our own instincts about our children in deference to the views and opinions of doctors and teachers, but, even if it is a scary thought, sometimes we do know better.

As far as the education side goes, education is surely a lifelong

adventure, not something to be crammed in before we reach adulthood; our son was a good student before he became ill, and, if he wants, can be a good student again when the time is right and he is healthy enough to benefit from and enjoy it. Right now he is a towering 6ft 3ins (I'm only 5ft 1in!!) who, after years of living within the boundaries of ME and pacing himself to fit them, is finding those boundaries getting larger and larger. His goal, his dream is to play rugby for Scotland and I am so proud to say he has a foot on that ladder.

'... do the thing you think you cannot do.'

Jane Colby's complete Witness Statement to the Judicial Review is in *The Brief 12* (this issue's pullout).

May 10 The Politics Show BBC1

In the run-up to ME Awareness Month the Trust worked on an awareness-raising feature with the BBC1 *Politics Show* and Samantha Brown, a student with ME. She was brought to an All Party meeting with Jane Colby, following which BBC reporter Max Cotton interviewed them on the Victoria Embankment.



Max asked Jane why someone who looked well should be entitled to benefits. She said:

'Suppose Samantha had asthma or epilepsy? Could you tell that from

looking at her?' Jane explained that after someone with ME has made a big effort, there is typically a delayed downturn afterwards. But people only see them in public when they're well enough to go out; they typically don't see the after effects. Samantha was unfortunately quite ill after her trip to Westminster.

We had good feedback from this programme. You can see the feature online: www.youtube.com/watch?v=uBBFpawh-WM.

July 8 Meeting of the Westminster All Party Parliamentary Group on ME

In this meeting, Jane called for the Trust's recommendations to alleviate the problem of mistaken child protection investigations of families whose children have ME to be taken up by the All Party Parliamentary Group as part of its future work.

'I would like to see if possible [...] a follow-up to the presentation that we made about child protection problems. [...] There were two very simple recommendations that we thought about quite carefully. They were put into the paper that I submitted with Joanna Smith, who was one of the mothers who came and gave evidence. I think those particular recommendations are doable. Some of the other recommendations that have come from other sources might not be, but I think that the two that we suggested are fairly simple and should be doable. If the APPG could actually consider how that might be taken forward, it might help ameliorate this problem which is still going on.'

On being asked whether she was going to make a specific proposal, Jane replied: *'Well, we did. In the*

presentation that I gave [...] there were two simple recommendations that could be made to help simply get over the misunderstandings. One was [...] to make sure that social services departments were alerted to the fact that ME in children is a case where statistically there is a huge anomaly [...] they don't realise that there have been so many false allegations in that area around the country, because they only deal with their own individual part of it. It is a case of some kind of alert being put out. It was worded carefully as to how that might be done.'

Chair: *'So, we really need to get the Inspector of Social Services to come and see us.'*

Jane: *'Yes. That would be very helpful. They simply don't see the wood for the trees. They see their own little tree.'*

Recommendations made to the APPG on 2 July a year earlier:

The Trust takes the view that The Department of Children Schools and Families should urgently alert Social Services professionals to the frequency of misunderstandings in cases of ME.

The Trust also recommends that a leaflet clarifying the procedures that should be adhered to by professionals in child protection investigations should be given to families under suspicion, and they should be informed of their rights.

See *Child Protection Issues: A Presentation to the All Party Parliamentary Group on ME* by Jane Colby, Former Headteacher and Executive Director, Tymes Trust, and Joanna Smith, Welfare Rights Advisor, Brunel University Students Union: www.tymestrust.org/pdfs/childprotectionissues.pdf.

**July 11
Royal Society of
Medicine Conference
'ME and CFS : Hearing the
patient voice' (part of the
'Medicine and Me' series)**

The Trust took part in this well-attended conference which we had assisted the Dean to arrange.

Dear Jane

Thank you so much for travelling all the way to the RSM on 28 January, and for your expertly texted messages!

I'd like to take this opportunity to thank you for all your expert guidance throughout the planning process; your comments, both at the planning meeting and in e-mails subsequently, were very important in steering the programme in the right direction and bringing minds together. And thank you for taking on the leadership role in representing all 5 patient groups. I can assure you that this has been an enormous help to me.

I do hope the meeting goes well and is found to be helpful, productive and worthwhile by all those with ME and CFS attending.

Very best wishes,

John

Dr John Scadding
Emeritus Dean
Royal Society of Medicine

**From the speech by Catriona Courtier, Friend of the Trust
Treatment : the patient's perspective**

I have ME. I have been ill for about twenty years. I also care for my daughter who is severely affected. [...]

I do want today to give a voice to the severely affected as they can't come to conferences and are not seen by doctors. Their experience is not always understood even by people with ME who are less ill. As Michelle Obama said, 'We are only as strong as the weakest among us.'

My first thought about treatment was - what treatment? Because most people with ME experience a lack of treatment. They are diagnosed. They feel relief. But rather than diagnosis being the start of a journey, it is the end of the journey. Many people turn to alternative therapies, often spending a lot of money. [...]

Housebound patients have no chance of a home visit from a specialist. Having a regular home visit from a nurse would be very much appreciated but is not available. [...]

Over the twenty years I have had this illness, what has really bedevilled the situation of patients with ME has been

the belief, which has been persistently promulgated that we are suffering, not from a physical illness but from an illness belief. This is at the root of all the problems we experience: the lack of resources, the hostility and disbelief from some doctors, the ignorance and disinterest in our symptoms, the ineffective treatments, the harmful treatments and in the very worst cases, the imposition of psychiatric treatment against the patient's wishes.

In 2002 the working group of the Chief Medical Officer said, 'ME is a chronic illness meriting significant NHS resources.' However, in the same year, an editorial in the Journal of the Royal College of General Practitioners questioned the validity of the CMO's report. It described patients with ME as suffering from PUPS, persistent unexplained physical symptoms and

said, 'illness belief and behaviour do not amount to proof of physical causes and there are gains involved in adopting victim status.' This was in spite of numerous research findings showing physical abnormalities in subjects with ME. At that time, studies had shown reduced blood flow to the brain, [...]

abnormalities in muscle mitochondria and so on and so on. Since then we have had research showing increased levels of cell death and research in London and Glasgow by Dr Kerr and Dr Gow using gene expression which has shown upregulated genes in patients with ME. In spite of this I have been told by a consultant physician who sees many patients with ME that ME is by definition an illness where there is nothing physically wrong with the patient. [...]

I do not believe that most doctors want to abuse or neglect patients. Those who promulgate the view that ME is an illness belief have undermined the mutual trust and respect that should exist between doctor and patient. They have done



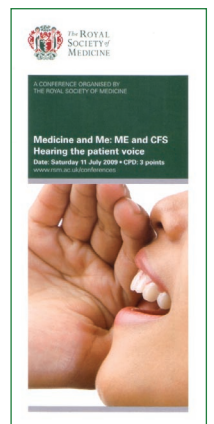
Catriona Courtier
Network MESH



Jane Colby
Tymes Trust



Dr David Misselbrook
Dean, RSM



a great disservice to both patients and to the medical profession. [...]

I now want to talk about pacing. Pacing was the approach to managing the illness that patients found most helpful in an ME Association survey. As understood by patients, pacing means doing what you can, doing a little more when you are feeling better, doing less when you are feeling worse. Activity can be broken down into manageable chunks, interspersed with rests and so on. It enables patients to enhance the quality of their life, even though they still remain ill. But pacing is not a therapy or a treatment. [...] When I was told that the clinic in west London intended to provide both pacing and Graded Exercise Therapy, I didn't understand how this was possible as they appear to be contradictory and mutually incompatible approaches to activity. However I came to realise that patients are being told to 'pace' themselves by gradually increasing activity on an incremental and consistently ascending scale. They are asked what they want to achieve, as if anything is possible. If I was asked, I would say, 'I want to achieve a Nobel Prize'! A patient in west London told me, 'I felt I was being shown a ladder with endlessly ascending small steps and being told I could climb it. I felt like screaming. I said that ME was not like that but I was not listened to.' [...]

I began by describing the severely affected as the weakest among us. In some ways they are the strongest. If people climb mountains or sail round the world single handed they are praised for it, but to live for many years with an illness like



Dr Charles Shepherd
ME Association

ME is also a huge feat of human endurance and courage but is seldom recognised as such. People with ME at all levels deserve to be respected. They deserve to be listened to and I would like to thank you and to thank the RSM for giving me the chance to talk and be listened to today.

**From the speech by Shannen Dabson, Tymes Trust Young Advocate
ME in children and adolescents : the patient's perspective**

My name is Shannen and I have had ME for 6 years. I found it difficult at first coping with the illness and other people's reaction to it. I turned so quickly from a lively, popular girl into someone who couldn't walk far, found standing impossible, couldn't abide the smell of food cooking, bright lights or watching TV and I soon needed a wheelchair. I achieved many small goals thanks to it. After the first summer I gave it back. By winter I needed it again. I was heart-broken when it was delivered - and to think I'd been almost excited with relief to see it first time around!

I have had some amazing highlights along the road to where I am now - living with the illness. The most life-changing ones have happened at home and I often couldn't even have a hug as a reward since my muscles hurt so much.

The hardest thing to maintain during my illness has been friendships. When you are 8 or 9 your parents still arrange your get-togethers. They drop kids over and you go around for tea. I could only stand 20

minutes' company before my head would be splitting, I'd become confused by words, have 'brain fog', become dizzy and need to sleep. My mum couldn't leave me alone and take the friend home and parents, no matter how well my mum explained things, couldn't be hassled to come over for such a short stay. Soon visitors trailed off. Before we'd often have a house full of kids. I got the feeling they thought they'd catch what I had! People didn't really understand and I hated having to explain it, or say how I was feeling. I wanted everything to go back to how it was. I started to get really low as I wanted it all to stop. I wasn't really living any more. I had to be carried everywhere, I couldn't even be alone on the toilet any more once I started to have fits. I used to enjoy being top of the class, going to athletics, being in the swimming club and riding horses. I couldn't imagine ever being well again. Now that I am older things are a bit easier as I can text my friends and they'll make their own arrangements to see me.



Shannen Dabson
Tymes Trust



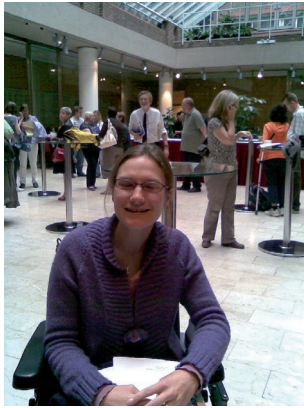
Hardip Begol
DCSF

Some friends I had to lose as they turned out to be fairweather friends. You'd be surprised how many there were. The friends I kept surprised me too. They weren't the people whom I'd have said were my best friends. I now have really understanding friends, well, most of the time - they are teenagers after all! [...]

My friend at school was diagnosed too. She does far more school hours than me but then relapses. She gets fed up with no one listening to her. She's struggling to please everyone

else and making herself miserable and ill in the process. She has no control over what she does. [...]

If I'd have gone the conventional route I may not now feel so optimistic and in control of my own life. I would not have the good friends and role models. I would not have my qualifications - 6 GCSEs. Instead, I may just have short spells of school attendance between relapses!



Naomi Hooke
Tymes Trust

Thank you to John Sayer for some of the RSM pictures.

September 12 ME and Viruses Should we be Worried?

Jane Colby's lecture to Worcestershire ME Support Group, one of the Trust's Partner Groups, on 12th September 2009. Reported by Daphne Caton.

Jane Colby introduced herself as the Executive Director of the Tymes Trust, member of various boards and committees concerned with ME/CFS for both adults and children; former headteacher and severe pwme when diagnosed in 1985.



Venue : Worcester Woods
Country Park

Her view is that 'classic ME' is caused by enteroviruses (bowel viruses) of which polio is a prime example and even scientists who accept biomedical causes put an undue focus on finding 'triggers' and 'perpetuating factors' when the virus itself amply explains these. A typical scenario is that a person falls ill with a flu-like illness, seems to get better but then develops ME symptoms which are a complication

of the original infection. She explains this as the original virus having gone underground in the tissues. She cites Dr Chia's research in California. He had found double-stranded RNA of enteroviruses in the stomachs of 82% of CFS sufferers. People continue to be ill because the original cause of their illness is still present and untreated.

Dr Betty
Dowsett and

Jane have been calling for ME to be made a notifiable disease since the 1990s - even if only among schoolchildren. While there was all this fuss about swine flu - shutting schools to contain the infection, notifying cases to produce the running total reported each day, government fliers and website, etc - nothing was done about ME outbreaks. There have been about 70 recorded epidemics of ME, mainly affecting children, with clusters of cases in schools and families which proves that it is infective.

A vaccine for ME cannot be produced until the infecting virus is identified but there is a problem with diagnosis. However, the enteroviruses can be found: a sample from the stomach using the protocol supplied

to Tymes Trust by Dr Chia can be collected in a hospital here and sent to California to be analysed by Dr Chia's team.

Jane produced evidence of bias in some NHS documents. They were suggesting that the 'perpetuating factors' are psychological. One had stated that previous personality suggested more likely reasons for continued illness than the infection; Great Ormond Street had stated that

a trigger might be viral but seeking a cause was not 'useful'; the Royal College of Paediatricians' algorithm for diagnosis had advised that if tests were abnormal it was not CFS. She further contends that the current recommended 'treatment' of ME/CFS actually favours the infective virus! Research from 1970 undertaken by US scientists including Dr Lerner showed that, in infected mice forced to exercise, the invading virus increased by 530 times! Other research has shown that exerting the body when infected caused deleterious chemical changes.



Jane Colby in
Worcester

Jane is working on a book to update and include the best of her earlier ME - the New Plague. There was insufficient time to go into details but she touched on one or two aspects:

- Polio = enterovirus
- Patients' voice needs validation: pwmes' accounts about their symptoms and reactions are dismissed as 'anecdotes' though 'the horse's mouth' is accepted in other contexts as the most reliable
- Detective stories/fairy tales etc are about truth/good/light etc overcoming falsity/evil/darkness etc. The same is needed in the sphere of ME/CFS
- Terminology is very important - but also a vast subject! She calls CFS an 'artificial construct' and is pleased to see this term for it being adopted elsewhere; she calls ME a 'discrete disease'.

Jane concluded her talk by saying that [as a writer] satire is a useful tool for debunking the more useless opinions and suggestions that abound about ME.

From the Question and Answer Session

I asked Jane what we can do where schools do not give child pwme

the concessions that they have agreed and should. Her answer is to contact the Trust (as reported in last March's Newsletter.) Each case has to be treated separately so she can't give a blanket set of rules of instructions. Parents need to be aware of their legal rights and to insist on them. The Trust can help with this on two levels: all the information on the website is free and open to everyone; for members there is access to an advisor for just such problems.

I expressed concern about recent reports of parents being punished for objecting to inappropriate medical interventions with their ME children and asked what they could do.

The answer again is to contact the Trust. They have a free publication on their website on Child Protection Issues and Dr Speight, who is part of the Trust's Professionals Referral Service, has experience in this field.

October 8 XMRV

In the autumn of 2009, new research from the Peterson Whittemore Institute in America suggested that a retrovirus, XMRV, might be the cause of 'Chronic Fatigue Syndrome'. This aroused great interest in the media and the patient population and we expect to see more research in this area.

At the moment, it seems unlikely to us that XMRV is the cause of classic ME. One reason is to do with the behaviour,

or epidemiology, of ME, which appears in clusters and epidemics.

There are a number of considerations. For example: If the XMRV retrovirus (like the HIV retrovirus which causes AIDS) is passed from person to person in blood and other bodily fluids (though not saliva or phlegm) then it would not adequately account for school and community epidemics of ME; secondly, the XMRV retrovirus has also been



Left to right: Jane Colby, Betty Hughes MBE, Honorary President of the Worcestershire ME Support Group, Ian Logan, Chair of the Worcestershire ME Support Group, Jill Pigott, Co-ordinator of the Worcestershire ME Support Group

discovered in men with prostate cancer.

It is possible that people who already have ME or prostate cancer (or maybe another disease) have the XMRV retrovirus as well, because their immune systems are overloaded by

fighting several things at a time. It is also possible that this could happen the other way round, with the XMRV retrovirus interfering with immune function, so other illnesses such as ME can develop because the body doesn't fight infections as efficiently as it might. Too little is known as yet, and no tests are yet available for XMRV in the normal clinical setting.

We still take the view of the ME experts like microbiologist Dr Elizabeth Dowsett, who maintain that classic ME is, and always was, an enteroviral disease (bowel virus) which the recent work of Dr John Chia in California would support. Whether XMRV is a second player in this scenario, future research will hopefully clarify.

Resignation from AYME

We do not normally comment on the work of other organisations in *Vision* but this year we have had to make an exception. This is partly because of evidence given of necessity to the Judicial Review, and partly because Dr Nigel Speight, the consultant paediatrician on our Professionals Referral service, with whom we have worked for many years, has issued the following statement:

Dear all

I just thought I should inform you officially that after a long and happy association with AYME I have decided to resign as their Patron.

Without going into too much detail I would say that over the last couple of years I have become aware that they have changed their position on several areas and that our views have accordingly diverged.

In particular AYME seem to have become more willing to collaborate with the medical and psychiatric establishment in order to appear respectable. This appears to have been the cause of AYME's relative enthusiasm for the NICE Guidelines, which most of us feel involve an overemphasis on CBT and GET. This compromise seems to have helped the psychiatrists to get a new lease of life.

The result of all this is that AYME appear to have alienated themselves from most of the other ME charities (with the exception of AfME who appear to be taking a similar position). In this controversy I feel more in sympathy with the rest of you.

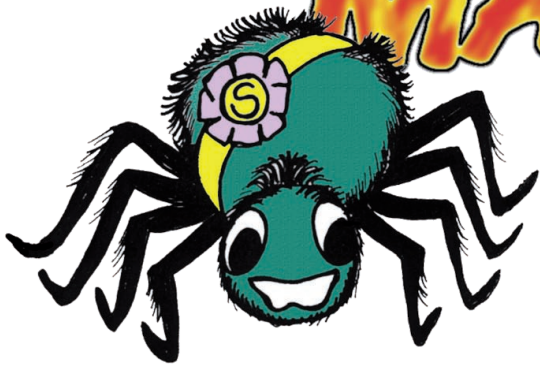
I have gained the impression that AYME no longer appreciate my opinions and prefer my status as their figurehead to be a largely silent one.

It is a combination of all these factors that has caused me to resign and I am sure you will all understand.

With Best Wishes

Nigel Speight

SEB'S MANOR



Sebastian Says

Happy Birthday to Us!
(not yet)

Happy Birthday to Us!
(in a while)

Happy Birthday Dear Ty-ymes...
(in a few months)

Happy Birthday to Us!
(ok, next year actually)

In 2010, we're 21 years old!

Being an Amateur Historian, as well as an Accomplished Artist and Poet who is Disarmingly Modest about his many skills (I never pretend I'm clever, I just AM clever and can write Very Long Sentences) I've been scrambling about in the Trust's Archives. (That means our history.) Look at the treasure I came up with.

Laura Shave drew us some big bold flowers with instructions: Write in the flowers about things that make you smile! So people did. Lots of people. One's by Jade Scarrott, who inspired our *Young Hearts* book and Young Hearts Day.

Do you remember doing any of these when you were younger? I'm keeping the names to myself to see if you remember yours! Let me know.

Congrats to our latest prizewinners too! I want to send loads of prizes so if you're not up to entering by yourself, get some help! I don't mind 'at all at all'. (It's the way you say it - I have Irish ancestry, did you know that?) Draw me dancing an Irish jig and that'll be worth a SPECIAL prize.



Hi!
Amber here!!
Chloe's got a really sore arm today so I'm just sending in Chloe's art work for the Seb comp.
Love Amber

PS Chloe says 'Hi' to everyone at Tymes Trust! You're her best friends.

Could your family help you enter our competitions?

Comps 'n' Stuff

Katie's Giraffe

On behalf of Mr Harley, Chair of Trustees, I name this giraffe 'Mr Neckinstein'.

Well done Victoria Webster for coming up with Such An Original Name. Mr Harley was Very Impressed.

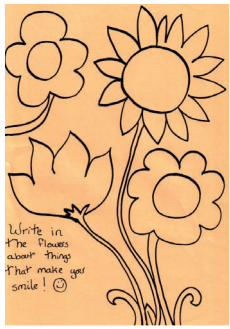
And well done to our two runners-up: Esmé Sensibar, who thought of Twig, and Vikki George, who suggested Gerry or Necky. They both win cuddly prizes.

Now, what are you going to send us? Take a look at Things 4 U 2 Do.



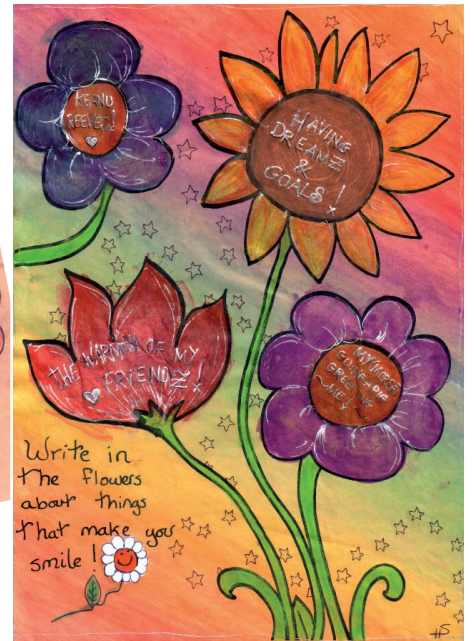
You're never too old to colour! One of these artists was 10, the other was 24!





What Makes You Smile?

hot chocolate with froth and sprinkles
the warmth of my friends



warm sunny weather
seeing other people happy

birthdays

God

learning something new
listening to music
watching comedy especially blue-tits
writing

kindness



knowing it's not long till I can give my Christmas presents



seeing the stars in the sky at night (the only time I can open my blackout blind is when it's dark)

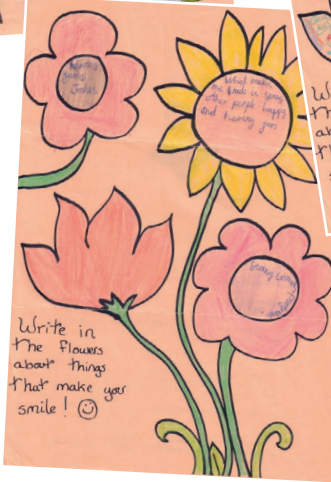
hearing funny jokes



seeing my mum

watching a good movie

having my brain come back from another planet
my guinea pig greeting me

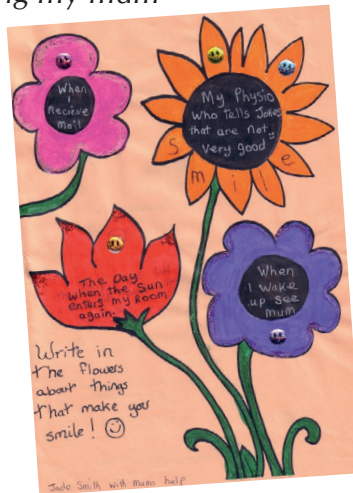


rain

first thing when I wake up

getting letters, texts & presents

watching my kitten and dog rolling around



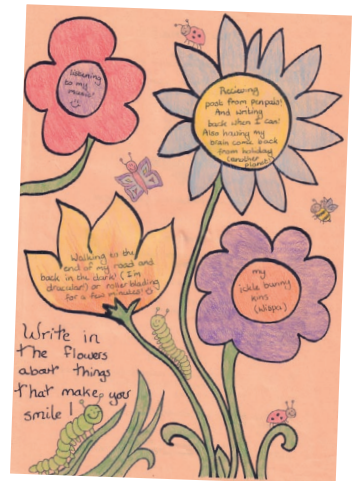
huggles

teddy bears

dad

chats

Jesus



Surprises from my Treasure Chest go to everyone who sends me something for my page!



A letter from...

Thanks for your concern about Esme and exercise - all of these activities have had to be completely stopped. Before we had a diagnosis she went to a local restaurant, walked to her dance class, did only 10 minutes of her class and then a day later did a piano exam. The next day she of course had a relapse and was off school for a month. We got a diagnosis of ME.

At present, she is slowly recovering to her previous (low) energy levels. Esme has not attended school since her diagnosis. I am struggling to know just how much of school she will be able to cope with as she can't stand for more than 20 minutes and sitting upright is on some days a challenge for more than 20 minutes also. This is all so new to us that my head is swimming with information. The school issue is a major one.

This photo represents the way ME people spend endless hours and days staring out from the very real prison of our bodies - we look down and see our knees, our feet, as if stuck to the floor - every movement seems impossible, heavy,

jarring. So many of us spend years like this, in our chairs, looking out on the real world - but we are the lucky ones, we can SIT a lot of the time. Some can only lie down.

Brigid O'Connor
From America



I have spoken to a couple of other mothers of children with ME via the Advice Line. This support has been really appreciated as I was feeling quite alone in dealing with it all. Thank you for pointing out the articles regarding education for children with ME. I couldn't quite believe that school could be such a drain on the nervous system.

Julia Sensibar

Useful articles available at www.tymestrust.org/publications.htm:

The SENCO's Key Role in supporting pupils with ME

Commissioned by Birmingham University School of Education. Shows what happens if a child is encouraged back to school too soon, and for too long.

Back to School

Published in *Special Children*, a professional journal for teachers.

I am glad that you had such good feedback from the Politics Show. Well done to Sam Brown too, for the clear way she put across her financial predicament and for speaking up at Westminster. I liked the portrayal of the symptoms of ME; Samantha's words and the way it was filmed gave a powerful impression of the illness. You made a good point that asthma and epilepsy are also invisible for most of the time. It is strange that people, including some who should know better, use the snapshot method to assess how well or ill someone is.

Pat Williams



Dr Elizabeth Dowsett (left) with Vivienne Mills of the Colchester ME Group. A long time colleague, Betty is one of the greatest specialists in classic ME and a microbiologist of international renown. She sends you all her love and best wishes.



Pat and daughter Zoe both have ME



Young Officers

of The Young ME Sufferers Trust

We have so far appointed a Young Advocate, a Young Artist, a Competition Champion, and now a Young Artist Overseas.

These appointments were made by invitation because of the skills of the young people, their enthusiasm, and their regular contact with the Trust. None of them are well. They do only as much as they want to do; mostly they get on with their own lives, which is exactly as it should be! We never ask a lot of them as their health is the

most important thing. Most of their contributions are entirely their own idea. The main thing is that they enjoy and personally benefit from being one of our Young Officers.



Testimony by Lisa Dabson:

My daughter has gained a great deal of confidence because of the Tymes Trust. They have given her



Kathryn's powerful artwork symbolises the wounds caused by being shackled with ME, and shows how, out of suffering, new life can blossom.

WISH I WAS DREAMING

If there's one thing I dread
It's the hours I lie awake in bed

Toss and turn I spend all night
Counting the hours till daylight

My body just won't sleep
I try everything even counting sheep

It wouldn't be so boring
But even the cat is loudly snoring

As I lie there I recall all the things I should know
Before I make a list they just as quickly go

To keep me company I have my pets
Who'll fall asleep first?!...place your bets

When to sleep I finally drift
I feel I've been given a perfect gift!

Laura Tadler

If we run out of room for your poems and letters, we save them for another time. Keep them coming.

a huge accolade by making her their Young Advocate. A title she bears with pride. This year it allowed her an audience with over 100 patients and professionals at the Royal Society of Medicine. More importantly it gave others like her the knowledge that they're not alone. For my daughter's voice is the voice of thousands of other youngsters.

Shannen has 'spread the word' about her difficulties due to ME. If my daughter had not had the benefit of a group such as the Tymes Trust influencing her life in such a positive, loving, gentle way she'd never have had the courage to achieve any of this. She is

fearless and does not take no for an answer.



Dear Jane,

I can't tell you how thrilled I was to receive your email today!!! It's the most exciting news that I've had all year. I am truly honored and so touched that you liked my artwork. It would be my pleasure to draw for Vision!

Again, thank you so much!

*Best wishes, Kathryn
Young Artist Overseas*



21st Anniversary Presentation

hosted by Colchester ME Self Help Group

The Colchester ME Self Help Group has invited the Trust to give a special birthday presentation in the summer of 2010, our 21st anniversary. Everyone is welcome, space permitting. Make sure you are registered for our Alerts at www.tymestrust.org so you receive full details and can let us know you intend to come.



Young Hearts Goes Global

'The foreword by Terry Waite is inspiring and profound.'
Maria from South Africa

'The illustrations are beautiful - the one with my essay is PERFECT!'
Kathryn, Tymes Trust
Young Artist Overseas



To explain ME to your family and friends, email them a link to our website. Ask them to watch the three-minute TV interview with Jane Colby on the homepage. This interview was with ITV Central News when the book was launched on our first Young Hearts Day. Young Hearts makes a perfect present. £7.95 inc p&p. Order online using our Donations form.



Mr Harley's Misbehaving Menagerie

At this time of year Mr Harley always sends out gifts free! All you have to do is ask.

Actually please do. We have quite a crowd here and they're all getting rather holiday-happy. There are London Beefeater Bears, French Snow Bears and Bears with Socks. There are two types of Snowmen, Mooses, Pups and Penguins. I think I saw a Duck and a Santa on a Stick. The few remaining Bobby Bears are struggling to maintain order.

FACT

In ME there is typically a delayed effect of effort. School attendance is often the biggest cause of relapse. You may look OK at the time and then be ill afterwards. At www.tymestrust.org you'll find free publications for doctors and schools.

Don't forget to let us know if you prefer not to receive birthday or Christmas cards for religious or other reasons. This service is personalised.

Could you give one of them a loving home? Send an email, phone in, write, or ask your mum or dad or sister or brother to help. Mr Harley is looking forward to being Santa again! Ho Ho Ho...

ME is the biggest cause of long term sickness absence from school. It is a serious, potentially severe and chronic neurological illness. World Health Organisation classification ICD10 G93.3