



# The Young ME Sufferers Trust

[www.tymestrust.org](http://www.tymestrust.org)

## TYMES MAGAZINE

Issue 47 Spring 2004 £1-95

### GREAT TREASURES

Dr Darrel Ho-Yen

### EXPLORING

The Physical Evidence:  
Latest Research

### THE DAVE MONK SHOW

A BBC Interview

The Tymes Trust/Nisai  
Education Partnership

### FEATURING SUPPORT FROM:

THE PRIME MINISTER

THE LEADER OF THE OPPOSITION

THE LEADER OF THE LIBERAL DEMOCRATS



# WHAT'S INSIDE

Dear Reader	3
Newshounds	4
The Chair of Trustees' Bear Awards	6
Tymes Trust Team	8
The Sky's the Limit	10
Behind The Scenes	11
The Dave Monk Show	12
Poetry	14
Exploring: The Physical Evidence	16
Great Treasures	18
Seb's Manor	20
Quotes-we-like	22
My Bedroom	23
Tymes Trust/Nisai Education Partnership	24

## TYMES TRUST DETAILS

**Postal Address:** PO Box 4347, Stock,  
Ingatstone, CM4 9TE

**Website:** [www.tymestrust.org](http://www.tymestrust.org)

**Partner:** [www.youngactiononline.com](http://www.youngactiononline.com)

**Advice Line and enquiries:** 01245 40 10 80  
Advice Line Hours: Weekdays 11am-1pm &  
5pm-7pm

Tymes Trust Data Protection Policy is  
available

Printing by Prontaprint, 11 Runwell Road  
Runwell Wickford Essex SS11 7PS

## TYMES TRUST

Registered Charity Number 1080985

Patron	Lord Clement-Jones CBE
Chair of Trustees	Keith Harley
Trustees	Jennie Whitlock Sally Player Alec Western
Executive Director	Jane Colby
Design	Kerry-Ann Edge
BWKT	Mark Colby

## WHAT YOU THINK

Thank you for all your magazines that you have sent me, as they have helped me to understand ME a lot better and it made me feel better to know that I'm not alone and to see that all my symptoms are actually something (that was before I knew anything about ME) so I just wanted to thank you a lot.  
**Love, Rachael Marshall**

Last TT mag was very good and think change of format of TT title good idea for those not in the know as to what you do.

**Alex Saunders**

One can immediately see when a website is run by an experienced webmaster: navigation is easy, as well as downloading. Well done Mark! I hope you realize how much your websites mean to people who are able to access them right across the globe...

**Mother of Katie, South Africa**

I love the purple site – it's great!

**Best wishes, Julie Neyt**

It's a super magazine as ever and I'm sorry I am not able to come to any of your conferences etc. We are honoured to be a Partner Group of yours.  
**Very best wishes, Julia, Clwyd**

Well done on a great magazine - keep up the good work.

**Claire Wade**

Many thanks for the copies of *The Forgotten Children* and *Back to School*. As always from Tymes Trust, they are excellent.

**Gill King**

Thank you for the information about your new website! I wasn't aware of it and managed to download the Autumn issue as a PDF file. This is absolutely wonderful and means you do not have to worry about sending us copies overseas. I referred a mother in Australia to your site, as well as the Alberta ME Association in Canada. Your excellent work reaches far and wide! A big thank you to the whole TYMES team – and love to Seb :)

**Love, Mary**

*Our ears are burning. Thank you all for your encouragement.*



Dear Reader

The theme of our Spring magazine is *Making It Happen*, with new medical research, new education methods and people campaigning and fighting injustice.

We are always moved by your letters, poems and emails. Reading your feelings, hopes and fears makes us even more determined to try to make things happen for you.

Our newest initiative is the Tymes Trust/Nisai Education Partnership. The law gives children and young people with medical needs the right to suitable education. ME also causes special educational needs. In *Removing Barriers to Achievement : The Government's*

*Strategy for Special Educational Needs (February 2004)* it states: 'A partnership approach is required with voluntary organisations.' You can read about our partnership with Nisai Education and over 30 Local Education Authorities in the Dave Monk interview. Maybe this scheme can help you?

Smiles are important too, so we haven't forgotten those. Even Sebastian (our Arachnoid Patron) has made things happen by leaving his virtual web to visit a young person with ME in the real world! We hope you like his photos. He says: 'a laugh a day keeps frustration at bay'.

Jane Colby  
Executive Director

## APRIL LAUNCH IN THE HOUSE OF LORDS

This issue of *Tymes Magazine* is being presented to all at the April launch of our education partnership. We are grateful for the support of The Prime Minister, the Leader of the Opposition and the Leader of the Liberal Democrats. You can read their statements at [www.tymestrust.org](http://www.tymestrust.org) or send an s.a.e. to Tymes Trust for a copy.



Prime Minister  
Tony Blair



Michael Howard  
QC MP, Leader of  
the Opposition



Charles Kennedy  
MP, Leader of the  
Liberal Democrats

## IN THE SPOTLIGHT: THE TYMES TRUST VIEW

Tymes Trust has issued a Statement on the Canadian Definition of ME/CFS (2003). In our opinion it is the best contemporary definition. It was developed for clinical practice and was compiled by physicians who have seen over 20,000 patients.

It addresses many misunderstandings caused by 'catch-all' definitions, which have so disastrously affected research into treatments and clinical practice.

We believe that under the Canadian Definition it is harder for people with 'chronic fatigue' to be misdiagnosed with ME/CFS. We also endorse the use of the name Myalgic Encephalomyelitis as used by the World Health Organisation along with Chronic Fatigue Syndrome, listed as a neurological disease under ICD10 G93.3. To

use another name means there is no official categorisation. There are arguments both for and against the 'itis' ending, meaning 'inflammation' but in our opinion the WHO name and categorisation should be respected.

The Department of Health tells us it recognises the WHO categorisation. After years of campaigning by individuals, by the ME Alliance including Tymes Trust, and by the Countess of Mar, the WHO Collaborating Centre in London is removing its dual listing of CFS as a mental disorder and also a neurological disease. Instructions from the WHO in Geneva make it clear that there can be only one categorisation for any illness and ME is neurological.

*Copies of the Tymes Trust Statement are available for £3-50 inc p&p.*

# NEWSHOUN

## 'I warned ministers about baby death expert three years ago.'

Evening Standard 26 January 2004

Jan Loxley-Blount's two children have ME and are registered with Tymes Trust. Jan, 'a former teacher and truancy expert who advised ministers in the seventies', began campaigning after her own children were almost taken into care by social workers using guidelines by discredited Professor Sir Roy Meadows, write Rob McNeil and Joe Murphy.

Professor Meadows coined the term 'Munchausen's Syndrome By Proxy' for people who damage others to get attention. 'His theories were discredited in a series of court appeals by mothers wrongly convicted of killing their babies. An estimated 5000 children were wrongly taken into care before his work was called into question' says the Evening Standard.

Jan said: 'I fought against social services and managed to get my children taken off the "at

risk" register but I realised that, if I could be targeted by social services because of this unquestioning belief in Meadow's ideas, then there must be lots of people less well equipped to deal with these sort of accusations. The letter I wrote to ministers in 2000 made it quite clear that a complete review of the diagnoses of Munchausen's Syndrome by Proxy needed to be undertaken.'

*Note: In 1999, Matthew Hill of the BBC Panorama programme and Jane Colby devised a questionnaire on ME and found that '7% of children from families questioned had been subject to child protection proceedings, and 4% branded with Munchausen's Syndrome By Proxy'. Contact the Tymes Trust Advice Line immediately if you need assistance with this type of problem.*

---

## alan franklin memorial fund



Tymes Trust has decided to keep open the Alan Franklin Memorial Fund as we are still receiving contributions. Dr Nigel Speight's thoughtful tribute as published in the British Medical Journal says of Alan:

'He made a major contribution to the welfare of young people with ME/CFS [...] through medical education and in his willingness to see young people for second opinions from outside his area. An avid steam train enthusiast, he participated in the rebuilding of the Ffestiniog steam railway in north Wales.'

We well remember Alan's steam train enthusiasm! But above all, his great compassion for children with ME. To make a donation to the Fund in his memory please telephone 01245 401080 or send your cheque to the Trust's offices.

*Cheques should be made out to Tymes Trust. Please write 'Alan Franklin Memorial Fund' on the back.*

---

## home education research fact sheet Ic

by The National Home Education Research Institute, USA

About 1.5 to 1.9 million children United States students (grades K through 12) were home educated in 2000-2001, and the number continues to grow. Dr. Brian Ray, in the most in-depth nationwide study on home education across the United States, collected data on 5,402 students from 1,657 families. Homeschool students' academic achievement, on average, was significantly above that of state-school students. In addition, the home educated did well even if their parents were not certified teachers and if the state did not highly regulate homeschooling.

## teenager seeks to overturn gmc judgment.

BMJ 7 February 2004 Clare Dyer, legal correspondent

A teenager with ME has 'challenged the decision of the General Medical Council to clear a paediatrician who interfered in her case without her parents' consent' writes Clare Dyer.

'At the High Court in London, lawyers for Miss A, aged 18, whose identity is protected by court order, accused the GMC of reaching a legally flawed decision in acquitting Christopher Cheetham of serious professional misconduct. Her counsel, David Wolfe, told Mr Justice Charles that Dr Cheetham, then a consultant paediatrician at Wycombe General Hospital, High Wycombe, had continued to intervene after her parents opted for treatment by a different paediatrician.

'If the GMC decision were allowed to stand, said Mr Wolfe, it would "fundamentally undermine the right of parents to choose between different medical treatment regimes for their sick child."' As we go to press, the court's decision is awaited.

Miss A's parents had declined an inpatient programme of psychotherapy and physiotherapy in 1997 when their daughter was twelve. They formally withdrew consent for Dr Cheetham to be involved in their daughter's treatment and consulted Nigel Speight, a consultant paediatrician from Durham with a special interest in ME, one of Tymes Trust's medical advisers. Dr Speight, writes the BMJ, 'agreed that she should be treated at home under the care of her GP. A local child protection conference approved the treatment and decided Miss A's name should not be put on the "at risk"

register. Mr Wolfe told the judge that Miss A had now substantially recovered.

'But Dr Cheetham had disagreed with the treatment and continued to try to influence it for a further two years, writing letters to doctors involved in Miss A's care criticising their assessments and treatment. He also tried to access her medical records without consent and asked for test results.'

When the GMC ruled in September 2003 that Dr Cheetham was entitled to act as he did, they considered that this was because the Children Act 1989 allows doctors to interfere if they have a reasonable suspicion that a child is suffering, or likely to suffer, significant harm.

But Mr Wolfe argued that 'there had been no suggestion that Miss A was in danger of being harmed. He asked the judge to declare that the law did not give a doctor a general right to seek to influence a child's clinical management simply because he disagreed with the treatment regimen, if that regimen was a recognised course of treatment by a doctor of unquestioned competence, and in circumstances where there was a range of different legitimate responses to the condition.'

An observation by Earl Howe in the recent House of Lords debate, reported in Hansard, perhaps describes this problem best. Commenting on the Countess of Mar's speech, Earl Howe said: 'In trying to summarise her concerns, I hope that it is not too colourful to say that we are looking at a doctors' battleground.'

---

## GP good practice guide on ME

GP magazine 1 December 2003

'A guide aimed at helping GPs manage young people with ME has been published by the Tymes Trust charity. Co-authored by a practising GP, who is a member of the CMO's Working Group on CFS/ME, the guide aims to help GPs ensure that youngsters with this condition do not deteriorate further and receive education suitable to their needs.

Contact the Tymes Trust Advice Line for details: 01245 401080.'

*You can also now download this Guide from [www.tymestrust.org](http://www.tymestrust.org)*



# THE CHAIR OF TRUSTEES' BEAR AWARDS



## Hello to the Chair of Trustees

I was reading the Winter issue of *Tymes Magazine* with my new pal Seb (when we eventually got the chance, after Cheryll and her mum, dad and grandparents had read it) and I saw the bit about the Beefeater Bears.

Now I know that Cheryll would love one of these bears as she has a very large collection of unicorns (over 100) and she would love a bear to watch over them and keep them safe for her. So I was wondering if it would be possible to send one to her.

I know what you're thinking – I would like the bear for company for myself. Well, I suppose it would be nice, as Seb has started packing his bag ready to come home and I will miss him soooooo much – we had such fun together! It would be lovely if one of the bears came to live here with Cheryll and me. It would really cheer her up.

Many thanks in anticipation.

Love,

**Fudge.** (Cheryll's Beanie Bear)

*Mr Harley says: 'Greetings to Fudge. I am sure you are right. A Beefeater Bear would certainly be good at watching over Cheryll's unicorns. Although it is generally kept secret, these bears are also skilled cheerer-uppers so I have no hesitation in granting your request.'*



## Dear Mr Harley

Hya. My name is Becky and I am 24 years old. I have had ME for 11 years and have been severely affected since March 03 when I had a bad relapse.

I need a Beefeater Bear to help guard my Eeyore collection. Not that I think anyone is going to come and steal them, but to guard them from running away to seek fame and fortune. Like Tigger, Piglet and Pooh have done. Eeyore might decide to make his own movie too. So I need someone brave and fearless to guard against this happening.

Yours sincerely,  
**Becky Noble.**

*Mr Harley says: 'I agree that it would be wise to guard your Eeyore collection, Becky. I have heard of dreadful things happening to soft toys that decide to go off on their own. Just think of the scrapes that Eeyores might get into, out in the wide world. I am sending you a Beefeater Bear to keep your Eeyores safe at home with you.'*





### Email to Mr Harley

I definitely need a Beefeater Bear in my room. My bed is constantly chaos! I always wake up to find bears have jumped from the side of the bed into the middle during the night and they are on the floor or worse still, being lied on, which I suspect is not good for their health.

Sometimes I wake to find my drinks half-gone and empty raisin packets in bed with me! Also my room tends to all of a sudden explode with messiness which I am sure is the work of some very mischievous teddies! So you can see why I need the hand of discipline when I am asleep.

Of course that is not all he would do. When I am awake and able to keep an eye on things myself there are many other important things he must do. I'm always losing the remotes down the side of my bed so it'd be a lot of help to have another pair of eyes.

I might send him to open the post or to look out of the window and tell me what is happening outside. When I am not up to going out I will send him in my place so he can report on activities and spend the next few days telling me all of it and helping me decide where I will go when I feel a little better.

There is a comfy spot for him right next to my head, so I will always hear him when he

I would like a Beefeater Bear to guard my ENERGY and to keep me company while I rest!

**Claire Wade**

*Mr Harley says: 'Certainly, Claire. And if your jewels need protection, he can do that in his spare time.'*



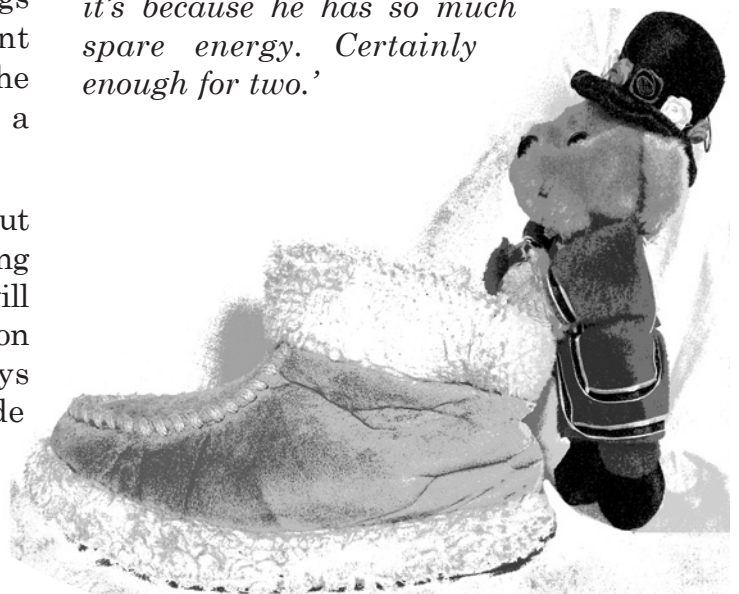
whispers and also enough room for him to patrol during the night.

You'd think he'd need some sleep sometimes but not this bear, he is a bear of adventure, fearless, superbear, sleep is just a waste of time for him, but I am sure he will rest his eyes when a hard day's work is over and he is listening to my deep breathing...

Superhero or not in the conventional sense, he would be to me, as he could be my ears and my eyes to everything outside.

**Eleanor Ward**

*Mr Harley says: 'We have the perfect Beefeater Bear for you, Eleanor. He needs plenty to do because he is exhausting us all here. I think it's because he has so much spare energy. Certainly enough for two.'*



# Tymes Trust Team



*Chris sent us a printout of him and his dog*

**NAME:** Chris Peachey

**POSITION:** Young Adviser and Young PR

**BACKGROUND:** I'm 18 and live in Herefordshire – originally from Essex with many steps in between! I've spent most of my time in education, but back in October 2000 I came down with a serious infection and after going through an exhaustive set of tests and scares, was diagnosed with ME. I'm now looking into home study higher education, volunteer and possibly a little self-employed work.

**HOBBIES AND INTERESTS:** Science, design, theatre work & acting, photography, world foods, films, reading, computing, music, sports – and friends.

**FAVOURITES:** Book – The Hitchhiker's Guide to the Galaxy; Music – rock, jazz and classical; Food – triple chocolate muffins, most fruits and a good Sunday roast.

**PERSONAL MESSAGE:** I'm always up for a challenge and adapting to life with ME is certainly one. I can be able to talk fluently one minute and be tongue-tied the next, be in bed for 24 hours or awake for days. This is all too familiar to both sufferers and observers alike. Like any challenge it's frustrating and often difficult, but also very rewarding. The key is to look forward to the next good time, not to look back on the bad. Take heart from every achievement, however small, and you'll find yourself smiling in no time!

---

## WE COULDN'T HAVE DONE IT WITHOUT YOU



Mark working on a Le Mans Prototype at Sebring, Florida

*Email to Mark Colby (Motorsport Systems Designer) who created and maintains our web presence:*

'Mark - Remember that severely ill young boy – the one whose mum sent a contact form from the website, with no return email address?

'We emailed the Internet Service Provider that you managed to identify from the data and explained the problem. We asked them to contact the family, who got back on the website and registered the details, so the Welcome Pack goes out today. Thanks very much for your help!'

*Reply from Mark:*

'Excellent. I was wondering whether the ISP would help or not.'

*Is there something you couldn't have done without a key person or organisation? Write and tell us.*



# Insight: Top Tips

## A good cup of tea primes your immune system against infection

You know the saying 'An apple a day keeps the doctor away?' Well, here's a new one: 'A good cup of tea is just great for ME!'

Scientists from Harvard Medical School and Brigham and Women's Hospital in Boston, Massachusetts, examined the effects of chemicals in tea on parts of the immune system called gamma-delta T-cells (the body's first line of defence).

In the laboratory, some of these cells were briefly exposed to an alkylamine antigen (found in tea). Researchers then exposed them to bacteria to simulate an infection.

The cells that had been exposed to the tea chemical mounted a strong immune response.

They multiplied up to 10-fold and secreted disease-fighting chemicals. But other cells showed no significant response to the simulated infection.

Two sets of volunteers were then asked to drink either 5 small cups of tea or coffee daily for up to 4 weeks (one pint daily). A fortnight into the study, gamma-delta T-cells from the tea-drinkers showed an enhanced ability to produce disease-fighting chemicals.

Coffee did not have the same effect. Other substances that give this benefit are apples, mushrooms and wine, but do not contain as much of the relevant substances.



*Proceedings of the National Academy of Sciences 22 April 2003*

## [www.tymestrust.org](http://www.tymestrust.org)

'Just visited your new website. Splendid. Love the colour, photos and all. I follow your efforts constantly and wish you every success.' *Audrey Adcock*

Have you paid us a virtual visit yet? Please go via our website when you purchase goods from Amazon as this helps our funds. No extra forms to complete. Many thanks.

## FEEDBACK ON THE TYMES TRUST VIEW Issue 46

*The Trust works hard to reflect your views and needs. Domiciliary services including diagnosis and care in the home seem to be sorely needed. Here are two examples of the feedback we received to our statement on the use of new government money for ME services.*

Thank you so much once again for a superb edition of *Tymes Magazine*. There were some fascinating articles about naps, exercise (viral particles) and doctors.

We were especially pleased with The Tymes Trust View about the government's £8.5 million – you have mentioned all the things that would make life so much easier for severely affected youngsters and their families.

It would have been wonderful to have this support for Claire over the years – we had it for our diabetic son, but only a poor overworked

specialist to help us with Claire and more recently an overworked OT. I know we are lucky to have had that, but hope that specialist nurses will soon be available for ME too – just a phone call is usually all we would need to help or put our minds at rest.

Thank you for all your hard work campaigning on our behalf. We are very grateful. Claire was delighted to see her letter on your back cover. She took such pride in completing the Treasure Hunt on her own.

*Anita and Claire Wade*

The points made in December's Tymes Trust magazine are spot on and ones I would totally endorse.

*Ian McIroy, Committee Member, Northern Ireland Campaign for ME/CFS Healthcare*

# The Sky's the Limit

**Teaching children with ME is a special skill, so teacher training is a regular part of the Trust's work. We encourage teachers to aim high and develop their own work in educating children with ME.**



Latymer School in Hammersmith is an internationally respected educational establishment with a centuries old tradition. Former students include Hugh Grant, Alan Rickman, Mel Smith, and many well-known politicians.

When one of their pupils developed ME, we were asked to run a course for the entire teaching staff in his year. We were delighted to welcome the Headmaster and Assistant Head Dr Jeremy Jeanes to this session.

Thurrock Pupil Support Service in Essex invited us to run a training afternoon for their staff. The Support Service has a number of ME pupils on its books and the whole team won a Thorntons Award for supporting two of them, who are also registered with Tymes Trust. The award was won after Lyn Walker, the Tuition Manager had attended the Tymes Trust London Day Course.

'I have had many comments from staff and colleagues about the value of the session and about the high quality and relevance of the afternoon. My staff from the Tuition Service found it particularly valuable, as we are obviously the ones dealing on a regular basis with young people with ME.'

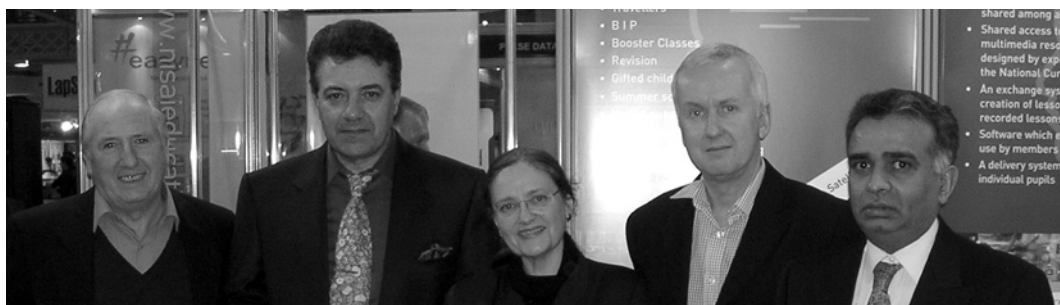
*Lyn Walker*



*Staff complete a group task as Lyn Walker discusses plans with Jane Colby*

The value of the Nisai Virtual Classroom was demonstrated recently, when Jane had to decline an invitation to lecture at the Nisai Education conference in the Midlands. She was meeting Charles Kennedy MP, Leader of the Liberal Democrats, in Essex on the same day.

Instead, she used the Nisai Virtual Classroom to give her talk over the internet. Jane explained that ME is more disabling than many other chronic illnesses and therefore causes more sickness absence. She discussed the confusion between ME/CFS and other conditions *eg* school phobia, anorexia nervosa, Munchausens Syndrome by Proxy.



*Dhruv Patel (Nisai) and David Teece (Warwickshire LEA) with Tymes Trust at the BETT show*

# Behind the Scenes

## Mind Games: The Inner Smile

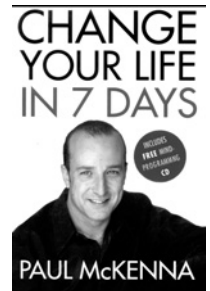
*Permission for this feature was kindly granted by renowned hypnotist Paul McKenna*

Sit comfortably – ultimately, you can practise the inner smile anywhere, in any position. Allow a smile to dance into your eyes. If you like, raise the corners of your mouth ever so slightly, like someone who knows a really great secret but doesn't need to tell it. Smile into any part of your body that feels tight, or uncomfortable, until it begins to ease or relax.

Smile into any part of your body that feels especially good. You can increase the smile by expressing gratitude to that part of your body for helping to keep you healthy and strong. Allow the inner smile to reach every corner of your body.

You can smile into your life as well as your body.

*From Change Your Life in 7 Days : Positive Software For The Mind*  
National Smile Week is 16-22 May.



## We meet Peterborough ME Self-help Group (MEET)

### A Tymes Trust Partner Group

Our December visit was billed as *A Festive Afternoon with Jane Colby*. The weather was freezing and those who braved the weather to be festive were congratulated! The cakes were extremely festive and we all made pigs of ourselves – well, Jane says she did.



*Tymes Trust members Hayley Rastall (11) and brother Richard (12) attended with their mother and grandmother.*



*Roma Porrick signed for Suzanne Foulstone (31)*

## PARTNER GROUPS

Shropshire and Wrekin Support Group ran a feature about our website and Clywd Support Group used their Partner Group entitlement to reproduce, without seeking permission, an item from *Tymes Magazine* – only they did seek permission because they used two!

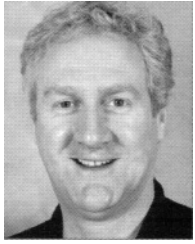
## Tymes Trust Book of Remembrance

'Thank you so much for setting up a Book of Remembrance to celebrate Dr. Alan Franklin's life, it's a very beautiful and fitting idea. Please find my contribution on behalf of everyone in the online ME Group I Got ME Babe.' **Caroline Phillips**

'My son David has had ME for nearly seven years now and we appreciate all the hard work put in by people such as Dr Franklin and yourself to raise awareness of ME and help those who have it. Thanks also for your consistently interesting and helpful magazine.' **Helen Leeds**

*The Tymes Trust Book of Remembrance for Alan's family is now closed. Thank you all for your many heartfelt contributions.*

# THE DAVE MONK SHOW



**Dave Monk hosts his own show every weekday on BBC Essex. From running a wine bar and bistro to lecturing in law, from owning a firm of solicitors to running a disco, his background is more varied than most.**

**Dave recently interviewed Jane Colby about the newest Tymes Trust education initiative. Could this be the educational answer for you?**

**Dave:** Earlier on today, we were talking about trying to educate your children at home and the first caller we had on 'Time to Talk' told a horrendous story – no education at all for the first three months when her youngster was at home with ME, and then seven months before she got a home tutor for one and a quarter hours a day. That's absolutely ridiculous.

ME is apparently the biggest cause of long-term sickness absence from school. Well, good news. Over 30 Local Education Authorities have taken on board a 'virtual classroom' to give pupils the chance of home-based learning, so this sounded really good to us.

Joining us is the Executive Director of the Tymes Trust, Jane Colby. Hallo, Jane, nice to see you.

**Jane:** Hallo - it's a while since I've been here, isn't it? We're using our full title now, so people know exactly who we are. Tymes Trust is for short - our full name is 'The Young ME Sufferers Trust'.

**Dave:** Right. The education authorities haven't – today on this programme – sounded as if they've covered themselves with glory up to now.

**Jane:** No. There's a lot of misunderstanding about the illness. Young people are often mistaken for being school phobic or for having other problems that might keep them at home, and not genuine illness.

A classic one is if there's more than one case in the family and they think the child is

copying. But clusters are common in families and communities and schools – it's just part of the epidemiology of the illness – and they can be so severely ill, some of these children. And it fluctuates. They'll have a best time of day, when people will see them - seeing is believing, of course -

**Dave: (nodding) Yep...**

**Jane:** - and then they'll have a worst time of day when they may not be able to get out of bed, they may be in pain, they may not even be able to remember a lot of words.

**Dave:** Yep. Virtual classroom. Tell me about it.

**Jane:** Oh, I think it's a brilliant idea. As you know, I worked on the Chief Medical Officer's Working Group for three years and we produced a report, and in that report it recommended home learning, e-learning, for most children with ME for at least part of their illness, because it goes on for so long.

And this is not just to protect their health, it's also so they can actually achieve something, rather than just dabble at it. The idea of the virtual classroom, for which we've gone into partnership with Nisai Education, is that it's two-way. It's interactive. It's not just a child trying to do a lesson at home which they've received on the computer. They can talk to the teacher. They can record the session and go back to it later, they can choose the time at which they watch it according to



when they feel well, stop it, pause it, whatever they like. *And* they have lessons to do.

It's not meant to be – as you saw, from all those education authorities who were taking part – it's not meant to be a competition between home-based education and firms trying to sell things – and the state education system. It's meant to be a partnership. And that's exactly what it is. It's a public-private partnership.

**Dave: So how do parents get their children into this?**

**Jane:** The easiest thing is just to contact us and we can put them straight through to the people who organise it. We've got a new website – [www.tymestrust.org](http://www.tymestrust.org) – or they can just type my name into Google and click 'I feel lucky' and they'll get straight through to my website.

**Dave: Does it cost parents anything?**

**Jane:** Not if the LEA buys into it. Some of them do it in different ways. It's Warwickshire Education Authority that is providing the actual lessons and it's Nisai Education which is the private firm that is facilitating the system. They had a stand at the BETT show recently, and we were there.

LEAs can either buy into it for individual pupils or they can buy into it en bloc and then any of their pupils can go onto the system. And it inter-acts with the local LEA in that a home tutor or someone from the home and hospital school can actually go into the home from time to time to check that the child is managing the system. So it's a complete partnership. And it saves them all the worry – the LEAs.

**Dave: Because one and a quarter hours a day is not enough.**

**Jane:** It might actually be too much for a child with ME! They can't do that *all in one go*. And I have to say, look at the length of time that child was without any education at all. If that ever happens to any of your listeners, that's actually illegal. After the child has been away for 15 days they're supposed to put in some kind of home tuition. Not seven months. Not two years.

**Dave: Well, we heard this morning – it happened.**

**Jane:** And it's an illegal thing. Parents have rights. There's a lot of misunderstanding by LEAs as to this business of re-integrating

children. I mean, we all think it's a nice idea, government would like to see it happen, but when a child is too ill, you can't re-integrate them without making them ill again. Over 90% of our calls that come to the Advice Line are problems with education.

**Dave: What subjects will be covered, and to what level? Obviously, the age of the child will vary.**

**Jane:** Of course. At the moment, they're covering from Year 7 up with main subjects such as English, Maths and IT and looking to expand. It's very new. The children who are on the scheme at the moment are really thrilled with it. This is going to grow. This is going to be demand-led I think, Dave. As you know, I'm a former head teacher from Essex, and Essex Education Authority, right back in 1991, asked me to launch the Guidelines for Schools that I'd developed with Dr Dowsett.

So I have had quite a lot of relationship with Essex Education Authority. I very much hope they will grab this with both hands.

**Dave: Well it could sort out so many problems for so many young people.**

**Jane:** Couldn't it just.

**Dave: There again, you see, I've had lots of people get in touch with me whose children are at home because they've been bullied at school and that's another major issue, isn't it? The bullies get more education than the victim of bullying who's been withdrawn from the school.**

**Jane:** Well, although it's our job to support children with ME, there are children who are out of school for other reasons and this scheme can be used for them as well – and *is* being used for them as well in some Education Authorities.

**Dave: And what's happening in the House of Lords?**

**Jane:** We're hoping that in April we shall be able to have a launch. We are looking forward to making this a high profile event.

**Dave: Jane, good to speak to you. Thank you very much indeed.**

# THE LIE

Fear was plaguing me in an alley of my doubt,  
Dark shadows of unknown creeping in and out,  
A mirror on the wall laughed and said its lie,  
'Look at you, you're nothing, kiss your dreams goodbye.'

Deep into my soul, cut the sharpened blade,  
The sorrows of my past, a wound that was made,  
A serpent on the floor hissed and said its lie,  
'Look at you, you're broken, your river has run dry.'

Falling in this pain, as I struggled on the slope,  
The weight on my back pulled against my hope,  
The mountain in my life loomed and said its lie,  
'You will never make it, the climb is too high.'

Weak on my knees, a cry was on my breath,  
The battle in my heart, a fight to the death,  
A voice in the wind chilled and said its lie,  
But something from within me rose up to defy.

Breaking through the chains in the prison of my head,  
A prayer from the heart, no word that was dead,  
A voice in the night, brighter than the sun,  
The truth of my saviour came to overcome.

*Robin Sansom 1998*



# DRIFTWOOD

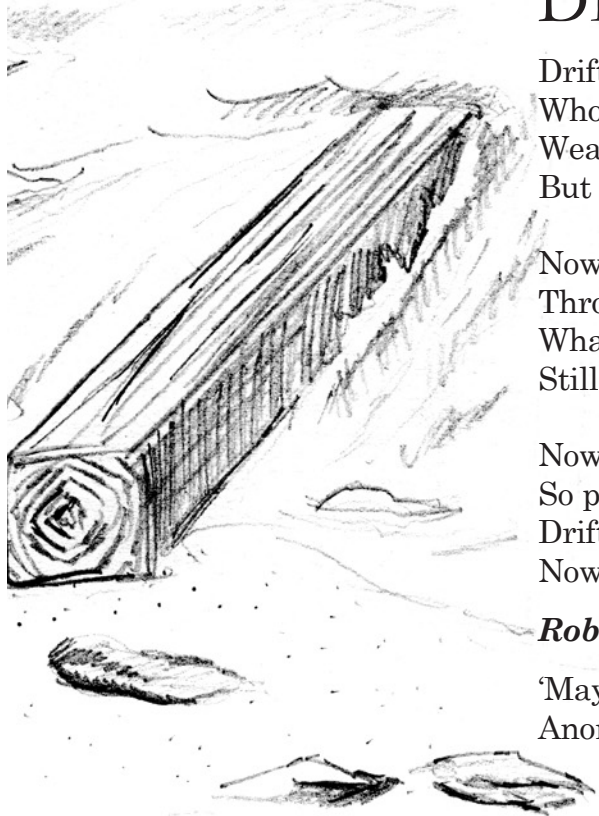
Driftwood, old driftwood, thrown upon the shore,  
Who knows how far you travelled, what leaves you once wore.  
Weary and forlorn, cold upon the sand,  
But your journey has not ended, it now finds you in a hand.

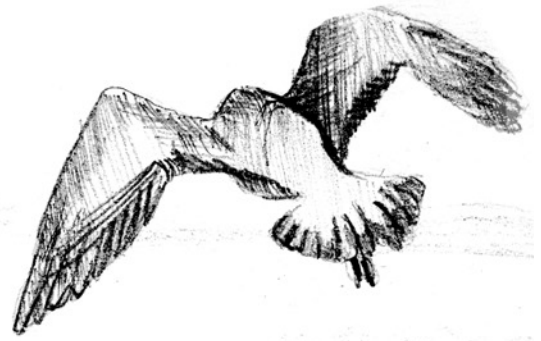
Now threatened by a knife, but gently it carves  
Through the outer rot where all is wet and scarred.  
What love holds this knife that cares to go so deep?  
Still believing that inside there's something left to keep.

Now finding that, old driftwood, you're still solid at the core,  
So precious is the goodness, in the secrets that you store.  
Driftwood, old driftwood, thrown upon the shore,  
Now you have great purpose – the handle of a door.

*Robin Sansom 2003*

'May the strength in your heart open the doors of your life.'  
Anon





## A MOTHER'S EYE VIEW

My daughter dressed herself today  
'That's very good' I hear you say  
'If she is two, or nearly three'.  
She's thirteen – and she has ME.

Such small achievements now, our aims,  
Not 'top in maths' or 'good at games'  
For that's the way it has to be  
When you are coping with ME.

Awake at night, in pain by day –  
The world a million miles away  
Adrift upon a choppy sea  
That's caused and fuelled by ME.

Some friends have stayed, and those we treasure  
Knowing friendship is life's greatest pleasure.  
Others have flown: it had to be –  
They couldn't cope with the ME.

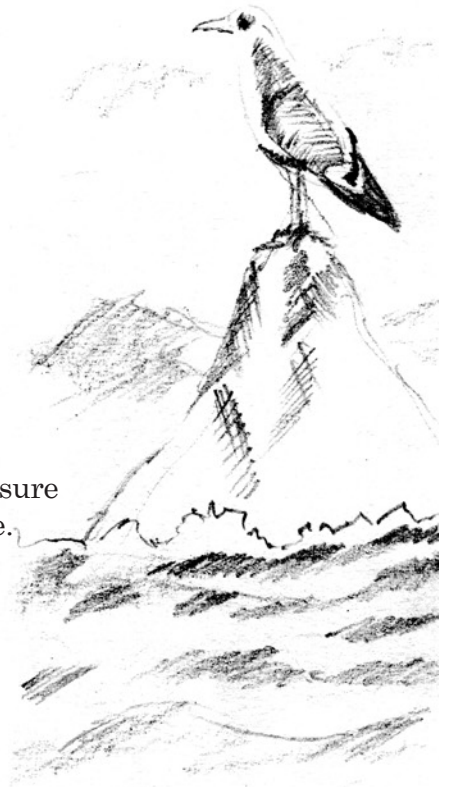
And yet, there are some brighter times.  
We laugh, and joke, and make up rhymes  
And notice things that they don't see,  
Who are not hampered by ME.

She's learned to smile to hide the tears,  
Gained wisdom far beyond her years,  
Learned patience and humility  
From this cruel teacher called ME.

*Gillian Stephenson*

Gillian writes: 'Robyn is now stronger. She's twenty and studying for her degree in maths and archaeology at the University College of Chester. She is pacing herself and getting a life.'

'It's important to find strength within yourself. Part of it is learning to live with it, part of it is learning to accept that you're not the same as everyone else so you have to find ways of levelling the playing field.'



# Exploring: The Physical Evidence A Newshounds Special

**One of the most hotly debated aspects of ME is whether it is related to poliomyelitis. *Tymes Magazine* explored this in Issue 45, Autumn 2003.**

We quoted from US Professor Richard Bruno: ‘Something has got to be damaging the brain. If the poliovirus does all these things to the brain and we’re finding the same sorts of things in ME as in the polio people, with the lesions on MRI scans, the endocrine changes and the failure of attention and concentration, plus all the subjective symptoms: if it quacks like a duck and it walks like a duck...

‘There’s got to be something underlying both conditions. And if all of these psychological and neuropsychological and clinical and physiological and endocrinological symptoms are the same...?’

**Here we highlight national press coverage of the latest evidence. Such press coverage not only influences the general public, but also informs GPs and other doctors who would not normally read specialist journals such as the *Journal of Medical Virology*.**

## Immune activation

*Journal: Clin Exp Immunology 2004 Feb; 135(2): 294-302.*

A study by Skowera et al supports the view that ‘CFS is associated with ongoing immune activation’.

This means that the immune system is busy, rather than defective. The observed activity could be due to an ongoing viral infection and this would fit with the French results. [see opposite page.]

The authors state: ‘Because we did not test for existence of any viral infections in our CFS patients we cannot exclude, or include, this hypothesis.’ They point out that because their results do not actually correlate with severity of illness, they could not be used as a diagnostic tool.

Their paper did not find evidence of allergies. Whilst people with ME are more sensitive to many chemicals and foods they are not generally thought to be more ‘allergic’ than other people. The word ‘allergy’ is often used loosely to mean ‘sensitivity’ but an allergy will tend to produce a quick reaction that can often be potentially serious eg peanut allergy.

## Brain test shows viral damage

*Mail on Sunday 21 December 2003*

*The Times, 22 December 2003*

Oliver Wright, Health Correspondent of *The Times*, reported on the work of a team of researchers at Hammersmith Hospital, London. The team scanned the brains of sufferers of CFS, which *The Times* points out is also known as myalgic encephalomyelitis (ME). Their results are backed by similar findings in Scotland and Japan.

The researchers found enlarged gaps in the brain; sufferers were low in a group of essential fatty acids, known as EPAs, high levels of which are found particularly in fish. Basant Puri, a neuro-psychiatrist at Hammersmith, said: ‘It was these natural gaps that we found to be enlarged in people with CFS.’

They found that when sufferers were later treated with fish oil supplements the gaps in the brain got smaller and they started to feel better. However, people taking fish oils should be careful about taking other vitamin supplements at the same time, so as not to have too much.

It is thought that the cause is a virus infection. The *Mail on Sunday* wrote: ‘Doctors may finally have solved the riddle of chronic fatigue syndrome or ME once written off by medical experts as a non-existent illness. Scientists using high-tech scanning equipment revealed that chambers inside the brain which are filled with shock absorbing spinal fluid are significantly larger in ME sufferers. Some experts had claimed the illness was “all in the mind”.

‘Dr Basant Puri, who led the study, said: “The damage is probably the result of a virus attack. Some people bounce back without too much difficulty, but others might be low in



essential fatty acids when they fall ill. In these patients, the virus may well damage the brain or alter its structure at the very least.” ’

*NB Enteroviruses, also known as poliovirus, coxsackeviruses and echoviruses are responsible for millions of infections each year, and have been implicated as possible causes in diabetes, inflammatory muscle disease, and chronic fatigue syndrome. They can also affect the brain.*

---

## Exercise – good for you or not?

*The Times 02 February 2004*

The Chief Medical Officer’s Working Group on CFS/ME reported in 2002 that ‘Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms.’ Deterioration after exercise is one of the classic symptoms used for diagnosing ME.

However, reporting an ongoing 5-year study ‘founded by the General Medical Council’, Peta Bee stated that an exercise programme appeared to be ‘one of the best ways to counter chronic fatigue syndrome’. Dr Trudie Chalder announced ‘The psychological benefits of following a fitness routine for people with CFS are great.’

One source of confusion may be the criteria under which patients are selected for studies. Chronic Fatigue Syndrome is a term invented for research purposes with several alternative sets of criteria. Some criteria will take in types of chronic fatigue that may be more amenable to exercise than ME.

For example, although sleep disturbance is a classic symptom of ME, the well-known study by Fulcher and White excluded anyone with sleep disturbance, yet the study was widely believed to apply to people with ME.

Doctors have been warned by their medical insurers to take as much care prescribing exercise as they do with medication, as it can cause adverse reactions. Tymes Trust cautions all those undertaking exercise, whether prescribed by a therapist or not, never to suspend their own judgement over the effect it is having.

Read ‘What does your doctor believe?’ and ‘Graded Exercise – does it really work?’ in the ME library at [www.youngactiononline.com](http://www.youngactiononline.com)

## Virus Seen in Muscle

*Journal of Medical Virology, December 2003.*

In the Winter 2003 issue of *Tymes Magazine* we reported on the work of RJM Lane and researchers at Imperial College, London, who recently found evidence for enteroviruses (the same family as polio) in the muscles of those with CFS. The RNA most closely resembled that from the Coxsackie B virus.

**This was linked to abnormal muscle function – 9 out of 10 subjects who tested positive for virus in their muscles had an abnormal response to exercise.**

This is most important knowledge, when placed alongside some of the advice given to patients, to follow graded exercise regimes.

A French team have now also demonstrated that persistent enterovirus infection in muscles may be to blame for some cases of CFS. Enteroviruses are bowel viruses that can mimic flu and glandular fever. Depending on the strain they can lead to polio and polio-like syndromes. There is general vaccination against three of those that produce poliomyelitis, so the others are in more widespread circulation.

Will Boggs of Reuters News reported that the French researchers detected genetic material (specifically RNA) from enteroviruses in 20 percent of muscle biopsies from patients with chronic inflammatory muscle diseases and 13 percent of patients with fibromyalgia/chronic fatigue syndrome, but not from healthy volunteers. These findings favour a persistent infection involving defective viral replication as a cause.

‘The persistence of defective or infectious enteroviruses is well established for a lot of organs,’ Dr. Bruno Pozzetto from the University Hospital Centre of Saint-Etienne, France, told Reuters Health.

Pozzetto said that Coxsackie B viruses seem to play a key role in persistent muscular infections. ‘To prevent this persistence, an inactivated vaccine directed toward these viruses could be indicated.’

The fact that not all patients demonstrated the viral presence is further evidence for sub-groups of CFS. Patients with the classic ME are most likely to be those affected by these viruses.

# GREAT TREASURES

**ME often causes isolation and loneliness. Friendships can be lost and broken through lack of contact. In the age of the mobile phone, Dr Darrel Ho-Yen extols the virtues of text. No, not that kind of text...**

Queen Victoria had a grandson who loved spending money. Although she recognised that her grandson was clever, she greatly disapproved of his reckless spending. So she was not happy when she received a letter from her grandson reminding her of his approaching birthday and that he would like some money.

In her own handwriting, she wrote a long letter to her grandson on the sin of extravagance and urged him to be more careful in how he spent money. She was surprised by his reply:

'Dear Grandma, thank you for your kind letter of advice. I have sold this letter for £5.00.'

Obviously, we cannot always sell letters for money! But letters are a great treasure.

## I love letters and I hate telephone calls.

### I love letters because:

#### Energy

Telephone calls are time-consuming and in my book *Better Recovery from Viral Illnesses* I advise patients to spend no longer than 10 minutes on the telephone. Telephone calls use more than 10 times the energy of writing a letter.

#### Reflection

A letter takes time to write and it should reflect your mood and situation. In contrast, telephone conversations are instantaneous and people slip into playing roles. Indeed, the first few interchanges of a telephone conversation are often very predictable. It is easier to say something important in a letter and the choice of words can be more appropriate.

#### Understanding the other person

When you read someone's letter, it is easy to stop and consider what the other person was thinking or feeling. The choice of words and how they have been used give you lots of information on understanding the other person.

#### Yourself

Writing a letter is a reflection of yourself. You should make personal comments and use phrases and words that you are happy with. It

is nice to try and be cheerful. It is wonderful to recount any funny stories.

#### Scheduling

The most important thing about letters for ME patients is that the letter can be scheduled into the day. Unlike the telephone, you are not forced to answer and you can choose a time that is most convenient to you. Indeed, there is the pleasure in receiving a letter and anticipating what is going to be said without even opening it. On a bad day, I would not open a letter on receipt, but I would leave it for the next day.

#### Reading again and again

A great advantage of letters is that they can easily be read again and again. Sometimes, you notice something on the third or fourth reading that you had missed when you initially read the letter. Telephone conversations, even when recorded, do not lend themselves to this repetition of pleasure.



A real problem about telephone conversations is that they use up a great deal of energy. Normally, when you talk to someone, you can see them and use all of your senses in detecting their mood and what they want to say.

With telephone conversations, you have to imagine the other person from only the voice; this uses up a great deal of energy and, more importantly, you have a limited amount of time in which to make all of these assessments.

In contrast, a letter allows you to pick it up, put it down, leave it for a day or a week. You work at your own pace and you are not forced to make assessments quickly.

---

Ideally, I like handwritten letters. You can tell – by how the words are formed and how they appear on the page – how a person is feeling.

All the time that my sons were at university, they wrote to me each week and I replied; I rarely spoke to them on the telephone. On the telephone, I could never tell if they were happy, depressed or anxious. They put on a show for me, as they did not want to worry me. Whereas, in their letters, I could read between the lines and detect their mood.

I still use fountain pens with ink and my sons believe that you can tell a lot from my handwriting as it changes to reflect my mood.

A letter does not need to be long. It can be short and still be very welcome.

Think of all the short phrases or comments made on greetings cards! I am a great believer in short letters that provide information. Sometimes, it is better to have a short well-written letter than a long rambling one.

The essence is to try and be joyful and to communicate some useful information. There is a great art in letter-writing.

I look upon all my old letters as great treasures. I enjoy reading and re-reading all letters.

I believe that all ME patients would greatly benefit from writing more letters. Apart from learning a very valuable skill, the letters you receive will be great treasures for you in the future.

I believe that this is true for everyone – even if your grandmother was not Queen Victoria!

## SHIRLEY CONRAN'S LETTER-WRITING PRIZES

When the telephone rang and best-selling author Shirley Conran announced she was donating £100 to the Trust for letter-writing prizes, we wondered – had she and Dr Ho-Yen been conspiring?

I promise you, they hadn't! Yet here was the perfect companion to Darrel's piece – encouragement for you to spend time with your pen (or your computer, because we know that some of you find it too painful to write with a pen). And if you're too ill to write at all, you may of course dictate your letter – but the words and ideas should be yours.

Don't worry if you're very young or very ill. Allowances will be made. And *everyone's* letters will be kept in a special file for display at events.

### What do you have to do?

We are extending the task that Shirley gave you in the Winter magazine, so anyone who already wrote to her can be considered for the prizes. All letters will be carefully read.

### Shirley wrote:

*I'm writing this in bed. I look at the sky. I look at the frost. I treasure my electric blanket. I stroke my cat. I enjoy my breakfast egg. I read Tymes Magazine. We all have so many things to be grateful for, and I enjoy the little things best. What little things do you enjoy?*

Write about the 'little things' you enjoy. Hopefully there won't be any frost left over in Spring! Send your letters to: Shirley Conran, Tymes Magazine, PO Box 4347, Stock, Ingatstone, CM4 9TE.

# SEB'S MANOR



by Sebastian the website spider (find him at [www.youngactiononline.com](http://www.youngactiononline.com))

## Beefeater Bear

My bear would have the important duty of watching over all my other bears, he would keep a special watch on them when I am asleep to make sure they don't get up to any mischief. As an additional duty he would also keep an eye on my jar of chocolate buttons - making sure my dad doesn't pinch too many!

Love Vikki George

*Mr Harley says: We have chosen a specially trustworthy bear for you, who will stop your dad from mounting a chocolate raid.*



Thank you for my gorgeous bag and fizzy 'bath bomb' - it was a lovely surprise.

Best Wishes

Claire Wade

## Colour Me In



Drawn by Laura Shave

## Hallo Everyone

Just to let you know I've arrived safe and sound in York. What a surprise it was for Fudge and Cheryll is delighted to meet me. I'm sure I will be well looked after. Please keep my web safe from those noisy hoovers for my return.

Love x Seb

## Dear Seb,

Great to hear that you've arrived safely. All hoovers locked up. Look forward to more later.

## The Tymes Trust Team

## Hallo again.

On my way back - I was getting a little websick so I came on ahead of the photos. Fudge is going to get a web camera (ouch) so that we can keep in touch on the internet.

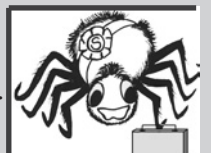
## Seb

In my absence, Matthew Eccleston suggested that Fudge be proposed for the Board of Trustees. I am of course not jealous. Not at all. No. No indeed. Not.

I am so not jealous that I have shared my editorial space with Vikki's Beefeater Bear request. Did you know they are really called Yeoman Warders? Very fierce. When necessary. Good for guarding smarties.

## WOULD YOU LIKE A VISIT FROM SEB?

Write and tell us why.



# Sebastian says:

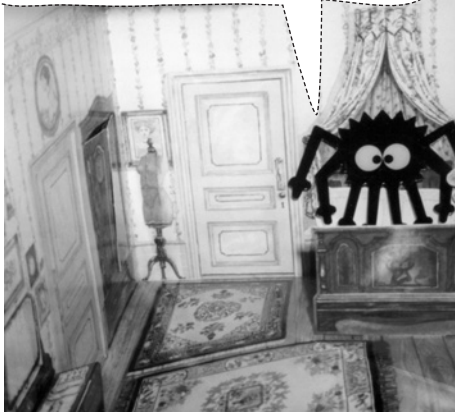
As Tymes Trust Arachnoid Patron, I thought it was time I visited some of you. A real visit, not a virtual one.

Here, I report on my great adventure to visit Fudge (Cheryll's Beanie Bear) and her family.

Naturally they took lots of photos of me, as I am so handsome. I was even able to exchange emails with Head Office (Read them opposite). Cheryll and her mum Julie sent them for me.

## Introducing first my lovely holiday cottage

My bedroom was so pretty!



In the lounge, Fudge and I spent lots of time listening to our favourite music: 'Running Bear' and 'Spiders from Mars'.

This is me in my dining room. The food was fantastic! Can you spot my private bathroom?



In our imagination, we went on lots of outings. They would have been real outings if Cheryll had been well.

We had a lovely day in London seeing the sites especially Big Ben. The weekend in Disneyland was magical.



Seb and me relaxing after our fishing trip.



Fudge taking me for a ride, I didn't know she is a secret biker babe.



Fudge and I went to the pantomime where I made a guest appearance



# QUOTES-WE-LIKE

Our readers usually choose the quotes for 'Quotes-u-like'. Last time we joined in – and we've done it again!

'When you've got ME you have to be really disciplined. You need to conserve your energy.'

*Shirley Conran  
The Observer Magazine  
1st February 2004*



'The doors we open and close everyday decide the lives we live.'

'Don't let life discourage you. Everyone who got where he is had to begin where he was.' *Anon*

*Sent in by Eleanor Ward*

## Eagle-eyes sought : A Spring Challenge

*Get out your Winter magazines again and spot the typo in one of our headlines. It's on the Quotes-We-Like page. There's a clue in the italics – and a prize if you can spot the typo. We didn't see it till December 23<sup>rd</sup>!*

'I am a nobody. Nobody is perfect. Therefore I am perfect.'

'The people who make a difference in your life are not the ones with the most credentials, the most money, or the most awards. They are the ones that care.'

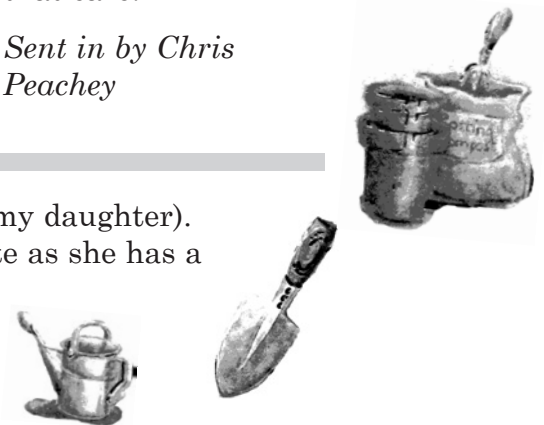
*Sent in by Chris Peachey*

Thanks for the really nice birthday card you sent Rosslyn (my daughter). It had a picture of plants in pots which was very appropriate as she has a lot of plants, as a fairly physically untaxing interest. So thanks again.

*Moira Carlyle*



**Colour me in** *Drawn by Laura Shave*



'The fight for a fair future must begin with education.'

*Prime Minister Tony Blair  
30 September 2003*

To All the *TYMES Magazine* Readers, a very special hello and lots of love and best wishes for the future.

*Cavan Kent*



# My Bedroom

Hi!

I thought I'd drop you an email about my room. I love my room. I have to spend all day in here, which I hate, but if I had to be anywhere I'd like to be in here!

It has blue walls and from my bed in the corner I can see everything. The 1st thing people notice is all my cards – my wardrobe, shelves and notice board are covered in them and they make something interesting to look at when that's all I'm able to do. Most of my stuff is reachable from my bed so it can get a little crowded in here – but I like knowing where everything is.

I recently got given some glow-in-the-dark stars, so now I have a little constellation. I couldn't put them on the ceiling though, so they've all ended stuck by my lamp. If I put them anywhere else they don't light up as I have bad light sensitivity, but my light seems to charge them up when I can have it on.

My bed is covered with teddies and cushions and usually a lot of socks! I also have a lovely cross stitch quilt that SWALK made me that makes me smile every time I snuggle under it.

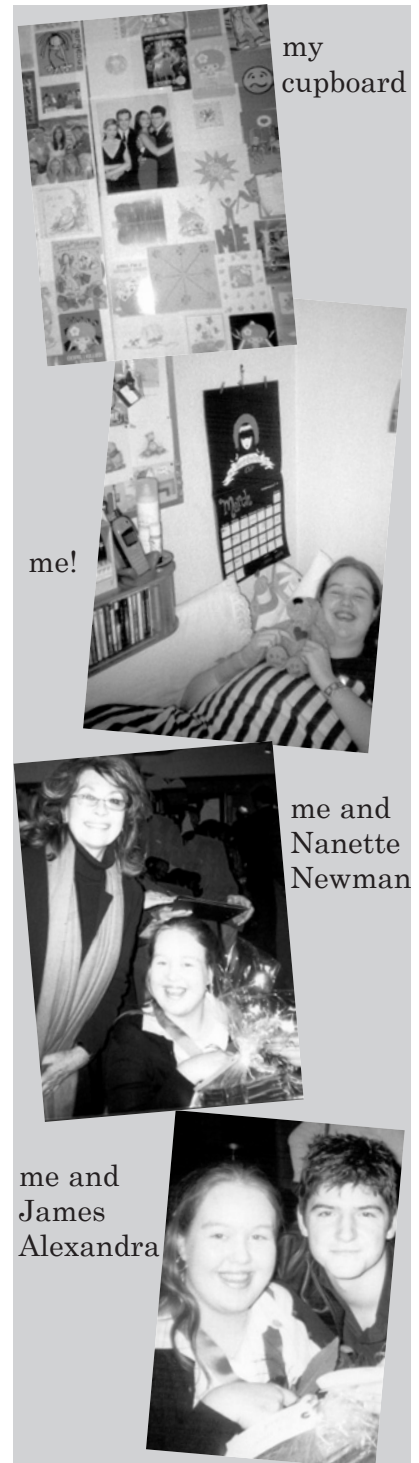
Then there is a lot of 'stuff'. I seem to accumulate loads of audio-tapes every time the library delivers them! A week ago the cover was covered in confetti from a huge party popper my friend Claire sent me! I think it shocked my mum when my sister popped it! Lol!

I like my room as it keeps changing and there's usually something new I can look at every day, whether it's a new card on my shelves, or confetti on me! Or even a new month on my calendar. Each card that covers my room has a story behind it that I can't help but smile at. I think it's hard to be cooped up in one place the whole time so it is the changes that help keep me sane.

love

*Eleanor Ward*

*Come on everyone, maybe we can send Eleanor some more cards for her room? Send them via Tymes Trust.*



Picture: Courtesy The Journal Series



The teddy that Anna donated was called Odysseus and became the official mascot for the 2001 Odyssey for ME. Anna was unable to take part in the long-distance horse-ride to Scotland but she raised over £375 over 2 years. This involved sitting in a supermarket; canvassing family and friends; local radio in Hereford and Worcester; local newspapers – and shops.

A by-product has been raising awareness and support locally, generating a better understanding of ME and informing young people with ME.

*Meg and Anna Daffin*

*The Tymes Trust Research Fund is now ready to be allocated to a research project. Watch this space.*

# Nisai Education Supports The Young ME Sufferers Trust

Tymes Trust attended the Nisai Stand at the BETT Show (British Educational Technology and Training)



**Oscar the talking DELL robot.**



**Oscar:** What magazine am I going to be in?  
**Jane:** *Tymes Magazine.*

**Oscar:** Wait a minute, Jane wasn't smiling. Take another photo. CHEESE.'

**Jane:** I'll send you a copy.

**Oscar:** Nice meeting you! Have some sweets.

## NISAI PRESS RELEASE

Nisai Education is supporting a drive by The Young ME Sufferers Trust to implement the e-learning and home-based learning recommendations for ME sufferers made by the Chief Medical Officer's Working Group on CFS/ME, published by the Department of Health in January 2002. [Endorsed by the Department for Education and Skills.]

Co-author of the largest epidemiological study of ME and an acknowledged authority on education for children with ME, Tymes Trust executive director, Jane Colby explains: 'ME is the biggest cause of long-term sickness absence from school and conventional education is a key cause of relapse. As a former head teacher, I recommend e-learning for many children with ME. It combines flexibly timed and live virtual classrooms, interaction with a teacher, and self-paced work to do when the pupil is well enough.'

Nisai Education sales manager, Stephen May, comments: 'The entire virtual lesson can be recorded and reviewed – a key feature for children with ME. The Nisai virtual classroom is used by over 30 local education authorities, hospital schools and City Learning Centres.'

Find the full press release at [www.supportit-uk.com/pressrelease/tymes.htm](http://www.supportit-uk.com/pressrelease/tymes.htm)

Lord Clement-Jones CBE is hosting the launch of the Tymes Trust/Nisai Education Partnership in the House of Lords.

