

The Young ME Sufferers Trust

2006-2

£2-95

Vision

YOUNG HEARTS ADVOCACY PROJECT

We give Young Hearts to
doctors and schools

CONSULTANT'S LETTER NOT REQUIRED

We meet the Parliamentary
Under-Secretary of State
for Schools

TEACH YOUR HOME TUTOR

Virtual seminar you can
watch from home

THE BRIEF

Journal of Clinical Pathology
publishes Special Problems of
Children with ME/CFS and the
enteroviral link by Jane Colby



Now 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 CBE
Patrons	Earl Howe Barbara Windsor Shirley Conran Terry Waite The Countess of Mar
Friends Patron	Lady Elizabeth Anson
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Printing by	Prontaprint, 11 Runwell Road Wickford, Essex SS11 7PS

Our data protection policy is available

Cover : 'Very pretty.' said Kinnerton.

'Now where's the cake shop?'

Our Patrons



Lord Clement-
Jones CBE



Earl Howe



Shirley Conran
OBE



Lady Elizabeth
Anson



The Countess
of Mar



Barbara Windsor
MBE



Terry Waite
CBE

Vision - The Project

As 2006 began, we identified a Theme for the Year : Children as the epicentre of ME. I am therefore pleased to tell you that the *Journal of Clinical Pathology* (from the same stable as the *British Medical Journal*) has published a Review of ME in children by our Executive Director Jane Colby, written as a follow-up to her lecture at the successful Invest-in-ME Westminster conference.



The Review is entitled *Special Problems of Children with ME/CFS and the Enteroviral Link*. We suggest that you bring this to the attention of your GP and your consultant. It discusses the special difficulties of children, shows how medical and educational

systems interact for better or worse, and signposts new medical evidence for ME as a relative of poliomyelitis. The full Abstract and the reference for the Journal's 'First Online' website is in *The Brief*.

The Trust fully endorses this Review, including the call for ME to be made notifiable due to its encephalitic pattern, and we welcome the support of Invest-in-ME in this.

Our position has always been that viral infection is at the heart of ME. We believe that school outbreaks are potential mines of microbiological information. The Dowsett/Colby study of UK schools (*Journal of Chronic Fatigue Syndrome*, 1997) demonstrated clusters of ME in schools and drew attention to a pattern of infection. New biomedical research such as that by Dr Jonathan Kerr, who also lectured at the confer-



Keith Harley

ence, reveals damage likely to have been caused by viral infection. Research into the vascular system (blood vessels) carried out for ME Research UK, also shows damage consistent with the viral hypothesis.

Another key part of our ongoing *Vision* project is to effect practical support for children with ME. Following our meeting with Lord Adonis, Parliamentary Under Secretary of State for Schools, we received written confirmation from him that a report from a consultant is not necessary before you can be granted support and that this is a misinterpretation by Local Education Authorities of government guidance. Full details are overleaf.

Representing the Trust at the Department of Work and Pensions, Jane Colby also identified contradictions and inaccuracies within the Department's proposed medical text for Decision Makers regarding Disability Living Allowance. Together with representations from the other ME organisations present, this means that the text is being re-drafted.

Finally - a reminder about the new postal system! Please make sure to put sufficient postage on your mail to us, as the Post Office is unlikely to deliver it otherwise. We value receiving all your contributions to *Vision*.

Kind regards

Keith Harley

Chair of Trustees

The Young Hearts Advocacy Project is Go!

We have been granted £3,254 from the Essex Community Foundation Local Network Fund to send Young Hearts to all secondary schools, surgeries and main libraries throughout our home county of Essex.

November 29th is Young Hearts Day, when we remember children with ME - could your school hold a special Young Hearts Assembly on the day? Ask your teachers now, as they have to plan well ahead.

Families, doctors and teachers all say this collection of poetry by children and young people with ME really helps them 'get inside' how the illness impacts on children.



Keith, Jane, Terry Waite, Karen Scarrott and Kerry-Ann Edge at Warwick Castle

Copyright Coventry Evening Telegraph

Foreword by former Beirut hostage and Terry Waite. In memory of 14-year-old Jade Scarrott. You can see more at www.tymestrust.org.

On the Things 4 U 2 Do pages you'll find special hearts to colour in. Take photocopies for your friends to colour, tell us how you're commemorating the day - and send us a photo for *Vision*!

Meet Our Patrons

Celebrity Support

Founder Patron Lord Clement-Jones, LibDem Spokesman for Culture, Media and Sport in the Lords, has hosted two Trust events at the House of Lords - a presentation of computers to children with ME, and the launch of the Tymes Trust/Nisai Education Partnership to bring interactive online education to children with ME in their homes. He regularly liaises with us on parliamentary initiatives.

Earl Howe, Opposition Spokesman for Health in the Lords, attended both our House of Lords events and contributed an insightful account to *Tymes Magazine*, the forerunner to *Vision*. He backs our work on child protection problems, and we have supplied evidence for the parliamentary review of MSBP/FII guidelines that are of great concern.

The Countess of Mar supports the Trust's biomedical research project with ME Research UK and has previously shared her personal experience of ME in a wide-ranging interview for *Vision*. She is a member of Dr Ian Gibson's parliamentary group on ME research, to which we have presented evidence.

Lady Elizabeth Anson hosted a champagne reception for the Tymes Trust Friends, (with delicious ME-friendly canapés!) at her London home, where young members, their parents, and supporters of the Trust heard her speak movingly about her personal struggle with ME.

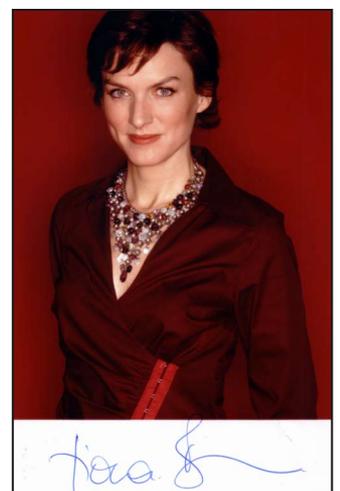
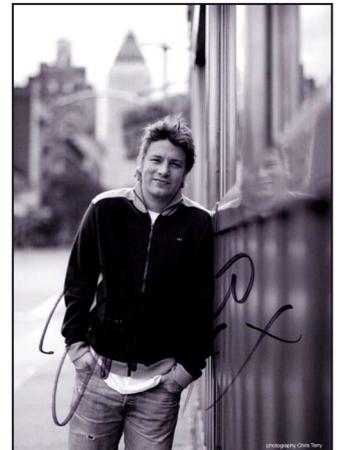
Shirley Conran gave her first public interview about her own ME for *Tymes Magazine*. She regularly contributes advice from her experience as a best-selling author and journalist, and has donated prizes for two Shirley Conran writing competitions. While running The Work-Life Balance Trust, Shirley also invited Jane Colby onto the panel hosted by Alistair Stewart at Claridges during Work-Life Balance Week.

Terry Waite launched *Young Hearts* at Warwick Castle on the first Young Hearts Day, having written an inspiring Foreword for the book. He gave us a long interview looking at similarities between the sufferings endured by a hostage and those of a child with ME.

Barbara Windsor, our most recent patron, planned to attend our second House of Lords event but was prevented at the last minute, to the great disappointment of some of the Lords present! She has sent several kind emails, stressing that her thoughts are with you in your long battle with ME.

Messages and mementoes have arrived from Kenneth Branagh, Fiona Bruce and Jamie Oliver.

Kenneth Branagh previously sent the Trust an amusing piece of encouragement for you all - a great pun on our name! You can see it at www.tymestrust.org or send us an A5 s.a.e. and we'll send you a print-out of the website page.



Buying gifts?

IN ASSOCIATION WITH
amazon.co.uk

We would like to thank all of you who remember to go via www.tymestrust.org whenever you buy things from Amazon. Without paying a penny extra, you make a helpful contribution to the Trust's work.

I'd like to thank you very much for the postal order which you sent me as the prize for the Shirley Conran Writing competition. I have used it to go towards an electronic Sudoku game, which keeps me entertained and my mind working when I can use it.

I'm sorry I haven't thanked you sooner, but recently I haven't been too good and I've had a lot of work to do on my OU course. Thanks again, Jane Fawcett :)

In The Spotlight

government confirms consultant's report not needed for home education

Towards the end of 2005, our Founder Patron Lord Clement-Jones, Chair of Trustees Keith Harley and Executive Director Jane Colby met with Lord Adonis, Parliamentary Under-Secretary of State for Schools. We are now pleased to announce the latest result of that meeting.



Under discussion was the insistence by schools and Local Education Authorities on a consultant's report before providing home-based education. It is a misinterpretation of Government statutory guidance in *Access to Education for Children and Young People with Medical Needs* regarding education in the home.



This misinterpretation comes from an LEA policy (appended, as an example, to the *Access to Education* guidance) in which the child's GP was cut out of the loop. This has led to unacceptable and repeated delays in suitable provision under the law, as we predicted when meeting the previous Under-Secretary of State. A GP is a qualified doctor and the Government own Exemplar *Megan's Journey* shows an LEA providing education in the home for a child with CFS/ME on the GP's recommendation.

LEAs' legal responsibilities include ensuring that *pupils are not at home without access to education for more than 15 days*. It is not possible except in cases of

emergency for a child to get to see a consultant within 15 days, nor, according to the medical profession, is it normally appropriate.

The relevant paragraph from Jane Colby's review in the *Journal of Clinical Pathology*, which you may wish to quote, states:

It is not commonly known that, although helpful and in some cases invaluable, there is no requirement for a consultant's recommendation for a child too unwell to access school to be provided with an alternative means of education. [...] The GP's recommendation, as a qualified doctor, is sufficient. After a meeting with the Trust, Parliamentary Under-Secretary of State Lord



Adonis wrote: 'It is unfortunate if, as calls to The Young ME Sufferers Trust advice line would appear to indicate, the advice in Access to Education is sometimes being misinterpreted as insisting that local authorities obtain a report from a consultant before action can be taken to provide support to children with ME who are unable to attend school full time. [On diagnosis] our guidance is quite clear. We say that ideally an early diagnosis should be made by a consultant paediatrician but we do not suggest that this is a requirement'.

At Lord Adonis' request, the Trust has provided the Government with real-life examples of good practice.

Tymes Trustcard Good Practice

examples needed from your schools

Lord Adonis, Parliamentary Under-Secretary of State for schools, is interested in the Tymes Trustcard. He has asked us to provide examples of good practice in schools, regarding use of the card. Can you supply us with examples?

Our anonymous survey of Trustcard holders showed that in general, their schools were supporting the use of the card. We were sent comments such as: 'I was able to get permission to go to the toilet', 'I could get my

dinner quicker' and 'I was allowed to go to the nurse.' Most people said there were no occasions when teachers were unwilling to support their use of the card, but if you do have any problems, please contact us and we will do our best to resolve them for you.

When you send us your good practice examples, please give us the details of the school. Send to Good Practice, PO Box 4347, Stock, Essex, CM4 9TE

what you think



Lynne Kersh and daughter Daliany

People came to the Invest-in-ME Westminster Conference from all four corners of the country and some from abroad too and the sun shone beautifully. The guest speakers' presentations were riveting and there was a firm consensus as to what ME is - a legitimate physical illness. The term ME met majority approval, together with the damaging effects of using the umbrella term CFS (Chronic Fatigue Syndrome).

Jane Colby's talk was excellent and her history of how the education Establishment has failed so many youngsters was like a perfect description of what my own daughter went through when she was of school age. The Tymes Trust's latest initiative to train teachers about ME sounds wonderful.

Lynne Kersh

The conference was excellent and well worth supporting.

Audrey Adcock
Mid-Devon MESH

Thank you for all the work you are doing. It is an uphill struggle - really a mountain range on a bad



day for ME sufferers.

Keep up the good work.

Conference delegate

Just to say I thought Vision was excellent, and the Essex Companion particularly useful. Would have helped me a lot all those years ago!

Sally Player
(now a Trustee of Tymes Trust)

Sally's son and daughter are happily much better now.

I think the Tymes Trustcard is a wonderful idea and has done a lot to alleviate my worries about

James beginning at senior school. I enclose a donation for Tymes. Keep

up the good work!

Madeleine Flynn

To apply for a Trustcard, email, write or phone for an application form. You can email us using the Contact Form on our website.



Please could I apply for a Tymes Trustcard - which was in the spot light of the recent copy of Vision - for my son who is currently attending school, he is 14 years old and has only just gone back to school after a year off through ME, I feel that one of these cards would benefit him greatly and he wouldn't have to give long explanations to different teachers regarding his illness. It is also easy for him to carry around with him.

I look forward to receiving our copy of Vision, it gives me so much pleasure reading the information it is packed with and I love all of the competitions. I was so pleased to be well on the

day we all received the cheque from the Millennium fund, it was great to see a picture of me and my family in the magazine. The following week I was ill again but, as I lay in bed I kept thinking of the special evening and I was so glad you got the cheque which allows you to continue with the wonderful work you are doing for the Tymes Trust.

I have had a long battle with ME but it makes me feel a bit better that I am not the only one with ME. I have missed a lot of my education but, with lots and lots of rest, which is best, I am at school mornings and some whole days! I love to be able to see my friends.

Love from Michelle Cross

With our Essex grant we produced the Essex ME Companion (a compact guide to managing ME) and sent it to all our members in Essex. It is now available for everyone free of charge from www.tymesrust.org/tymespublications



WHAT HAVE YOU BEEN DOING?

I am Samantha and I am 16. I have had ME for longer than I care to remember, possibly 12 years of my life, but gradually worsening until aged 11. I had to quit school.



It was the day of the FA Cup Final when we went out collecting for ME Awareness Week. We wore flowers in our hair and claret and blue ribbons for West Ham. I'd already grown lots of sunflowers, nasturtiums and geraniums so we could give people a plant for every donation made. We stuck information into the flower pots and had leaflets too. We photocopied 60 leaflets but it wasn't nearly enough. Everyone wanted to know more. One man gave us £10! The adults were in charge of collecting and I and my mates did everything else. We were out for 2 1/2 hours and raised over £200 for Tymes Trust. We had

I only managed one term at secondary and I was off more than in school. It really upset me. I have been bedridden often. Mum did everything for me in candle-light as it hurt so much to have anything brighter....

Samantha McKenzie

THIS YEAR SAMANTHA MANAGED TO ATTEND HER SCHOOL PROM, ALTHOUGH THE EFFORT OF THAT COMBINED WITH TAKING HER EXAMS HAS CAUSED A RELAPSE. WE ARE ALL ROOTING FOR HER.

ice-cream and a drink at 11.30. My nan, who's 80, had her snack in the road! Whenever a car stopped for her she told them it was ME Awareness Week and asked for a donation. People were in a cheerful mood because of the football. Flags were flying and people were chanting. It would have been a perfect day if West Ham had won.

helped... Sophie, Keziah, Sian, Denise, Francesca, Grace. I couldn't have done it without you!

A big thank you to everybody who Shannen Dabson



Sophie, Shannen, Sian, Kezia, Denise, Little Maria, Francesca and Grace



It would be lovely if you could send Emma something as a surprise to try and help her get through this dark time.

Thank you.
Adele (mum)



We had a raffle of some wooden toys my grandad made at a local fete. Unfortunately it was a very hot day; not many people came but we still made £50 which I enclose.

Best Wishes,
Katy Brackston



Katy and Alice

SO WE DID!

Thought you might like to see where I've been on my virtual holidays.



I've been looking at pictures and finding out about it. Looks lovely.

Wish you were here (and me!)

Love, Emma Gray

THE ENFIELD ASSOCIATION OF VOLUNTARY YOUTH CLUBS PRESIDENT'S CUP

To our amazement & delight David took the top award in a ceremony at Enfield Civic Centre. The award was in recognition of David's work with Children's International Voices of Enfield, and the choir of Christ Church, Southgate. Particularly recognised were: his GCSE Music composition Sailing which he reworked for the choir of CIV to perform; solo saxophone performances in Children's Voices Concerts; singing in the Children's Voices Choir & Chorale.



David also sings with the Choir of Christchurch Southgate, for whom he composed a Communion motet on O Saviour of the World which was performed in the Church on Good Friday. He plays with and has composed for the Barnet Schools Saxophone Ensemble.

Jan Loxley-Blount

Jan Loxley-Blount

IT'S LOVELY TO HEAR WHEN ONE OF OUR MEMBERS BECOMES WELL ENOUGH TO DO THIS KIND OF THING.



JADE SMITH'S DRAWN PATCH, HER TRUSTY DOG, AND SENT US A PICTURE OF HIM SITTING ON HER TUMMY! EDWARD BROWN TELLS US SKIP IS VERY EXCITABLE!

ALL OUR DOGS HAVE NOW FOUND GOOD HOMES!



Hi Mark

I thought you might like to see how Skip is getting on.

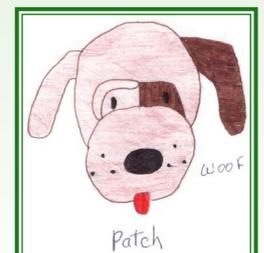
Here are some photos of when he first arrived!

From Edward Brown

Meeting the rest of the gang

Skip spots Lambo (the toughest lamb in the land)

He decides to try out his sheep herding skills (unfortunately he found out he doesn't have any!)



by Jade

Meet The Team



Shannen Dabson

Tymes Trust
Young Advocate
Age 11



This is from Shannen's address to Havering PCT Young People's Conference at West Ham Stadium. She managed 3 pages and her mum read the rest. Shannon says: 'They wanted to know what the doctors were doing wrong and I felt a bit rotten telling them because they were all so nice and understanding!' We were so impressed we asked her to become our Young Advocate.

My name is Shannen and I have ME and a heart condition. Some doctors I've liked, as they've been friendly and warm. Others didn't think I was ill and just told me to do more and get out every day.

My mum tried to tell them how seriously ill I was but no-one would listen. I'd spent over 18 months trying to get better but often getting worse and I was fed up going to hospital when they couldn't even get my name right. To some I'll always be 'Shaneen Dabson'! Doctors often didn't believe that my life was so limited or that I needed a wheelchair - they'd say 'but you look so well.' They'd never seen me well. Do they think that children of 8 want to spend so much time in bed? Do they think we enjoy it? We have to sleep until we're better and we can't get better until you believe that we're ill.

My ME was relieved hugely when they realised I had a heart condition and I was rushed into intensive care. I still have bad bouts but I've never needed a wheelchair again or been in so much pain. I can do more now without conking out or fitting. I still feel rough afterwards, though.

Having a long term illness you see doctors in a different way. It's not like in Holby City. You don't get friendly with most of them even though you're a regular - I don't always see the same doctor. Some look at you and they're thinking, 'I wish you hadn't come to see me.' It's like they've got this job no-one else wanted. A few have a laugh and a joke with me and remember I like rabbits and Quavers (Dr Who). I think this is important as the hospital trip might be the only day out in over a week. I also think if I've saved energy to go to an appointment and given up things I should be seen on time. I couldn't figure out why I'd have to wait two hours for a 5 minute slot. When I see the doctor a funny bow tie or terrible hair is good, as is an interest in books or Dr Who. It gives me something nice to remember and I don't feel like an NHS number.

Fatima's Vision

Update on the London Marathon

We said we'd devote Fatima's funds to the printing of this issue of Vision. Her run raised £924 - almost the exact cost of the print run. Spooky.

TXT from Fatima: 'SUPERB SUPERB SUPERB ... I am very happy to hear that the amount got to close to a grand!'

And one sent just after the race, when she was still hurting: 'I am very happy + grateful that I have the strength + support of many to do so little 4 kids who deserve so much.'

I did get fed up hearing that my pen pals and other kids all over Britain were having the same grief. Doctors need to put more in writing for schools to save parents so much paperwork. Parents need to look after us. My mum couldn't get out to even post a sick-note.

Luckily my family were clued up. Tutors should be too though. They shouldn't say that they won't teach you in your pyjamas or in bed and they should know your illness and that you can't get out and about when they ask.

I had more chances of winning the lottery than doing some of the goals I was set. These people didn't know me and didn't listen. It'd be all my fault, or my parents'. Once I'd been in hospital for four hours and as I was leaving the doctor said, 'Off to school are you?' The lifestyle of an ME sufferer is lost on most of them. It shouldn't be, or when we're older we'll stop seeing doctors.



Shannen and her friend Bethany with Jane Colby and Lady Elizabeth Anson



Peterborough ME/CFS Self-help Group Balloon Race

A Partner Group to Tymes Trust run by Diane Newman

It really was an excellent day, despite the rain and wind! The person in charge of the balloons (which were in two shades of mauve) said it would have been dangerous to use any net because of the force of the wind. It was in the midst of the city's Cathedral centre, with many members of the public passing through. However, it did not dampen the spirits of all those present, including volunteers, many of whom themselves had ME or with children affected by ME. We positioned our stall, which had

The Young ME Sufferers Trust leaflets and a number of its factsheets available, under the Guildhall building tower, where we all sat sheltered from the rain and wind drinking hot drinks and snacks!

Throughout the event, we were greeted by members of the public who bought balloon tickets from us and had their photos taken. It was a fun event and we managed to raise £700 for Tymes Trust!

Would your local ME group like to become a Partner Group to the Trust? We will support their work with young people and give permission to reprint articles from Vision.

Insight



I love travelling. When I'm strong enough, I take my motorised scooter on the train and use it to get around London for meetings! I pack a blanket, mackintosh, soup and hot chocolate, bananas, salad, and a handy bottle of water. (A large bottle goes in the luggage pack, in case of train cancellations or hot weather.)

I book with the Assistance Line, who ensure a ramp for wheelchairs and mobility scooters. Mine was bought to fall within UK train dimensions so I can get on most trains. Once on board, I rest my head and neck on a small blow-up cushion and wear dark glasses against bright lights and fast-flashing scenery.

I try to go early to miss rush-hour. I map out my route across London, Birmingham etc well in advance. Missing the traffic helps when I have to travel off-pavements - not often, thank goodness! London without thousands of tourists milling the streets is a rare and beautiful sight.

When visiting the House of Commons, I'll stop along the Thames for a bite to eat or, when near Regent's Park, I'll 'lunch' with resident pigeons, who are very well behaved - they just sit nearby and wait to be fed. The other morning in Regent's Place I heard the familiar sound of horses' hoofs and turned to see more

than 30 horses from the nearby Queen's stables trotting three abreast with a rider on the middle horse. What a wonderful sight!

People are generally polite and helpful - you can get humorous remarks. The best was when several of us with wheelchairs and scooters (can be borrowed from Shop-mobility for a 'stroll' through the park or shops) went through our Town centre and a man called out 'Cor! It's like Brands Hatch.' Of course, all those who heard him laughed. I also get 'Brrrrrrrr!' (racing car engine) when passing teenagers. Everyone laughs and young children look, as much as to say 'Wow, I want one.' I heard a little boy ask, 'Dad, can I have one of those?' People have names for their scooters. I just call mine 'batmobile' or 'chariot'.

It certainly has opened up my world. Having improved over the years, I'm still limited in walking, but now, when able, I visit the park, do light shopping, and of course, travel. After-effects can be quite profound in terms of exhaustion and overall weakness (body, brain and speech) so I've learnt to conserve energy for some time beforehand to avoid a 'crash' lasting days.

Diane Newman



Things 4

U 2 Do



Susie's left the central heart blank for your own ideas. You could decorate it, or write 'I love u Mum!'

Friends can colour photocopies, they could write 'Young Hearts Day 29th

November' in the heart and ask a teacher to put them up in school - get someone to take a photo for us!

Send us yours to see - we'll give as many prizes as we can and we'll post it back if you send a large stamped addressed envelope.

Name
Age
Address
Postcode

COLOUR SUSIE'S HEARTS

When I can't sleep at night
 It can give me a - - - - -
 If I hear the - - - hoot
 'Cos it's eerie, not cute!

People say the owl's wise
 'As it's got great big - - - -
 Is it evil or - - - -
 Out there in the wood?

Find the missing rhymes. We'll send you a little prize you can use in bed! Remember to count the dashes - one for each missing letter.



SNOWY WINDOWS

We've got snowy window clings to brighten up your room for Christmas! If you'd like some, let us know. We can omit Christmas images if you don't celebrate Christmas. Tell us a bit about your religion; we'd love to hear what your family celebrates and when.



THANK YOU SOPHIE!

My local Post Office had a collecting tin - which I made - beside their till last month and I am forwarding the resulting collection of £28.58. Sophie Baggs

Sally says:

What a great idea. Why not have fun decorating your own container? Be creative and send us a photo of you with your unique collecting box.

You need something strong enough - a Pringles tube, a baby milk tin, a chocolate box, a square tissue box... Cover it with greetings paper (we'll send you a sheet of Christmas paper if you like). Or use poster paint or emulsion (a water-based paint that doesn't make fumes!) Stick decorations on eg ribbons, self-adhesive stars, or plastic jewels and cut-outs sold for home-made greetings cards.

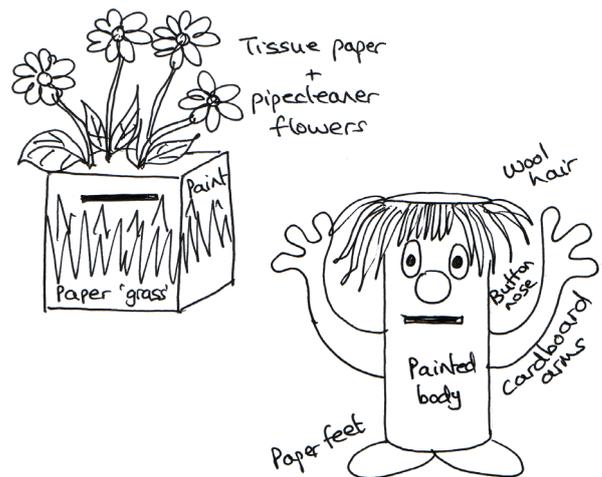
Tissue boxes have an opening in the top - you can just make it smaller. If you use another container, get adult help to make a slit safely - somewhere for people to pop those pennies in.

Make a label saying:

"Thank you for your donation to The Young ME Sufferers Trust, Registered Charity No 1080985"

When your collection is finished, send us a cheque for the right amount or ask an adult to pay online at www.tymestrust.org/donations - every little helps. We look forward to seeing those photos!

PS You could make something really wacky like these!



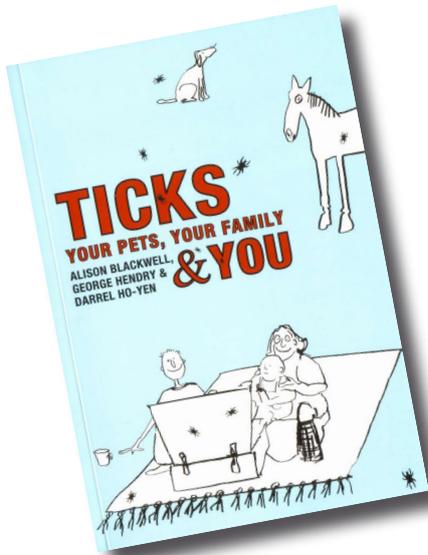
Quotes-U-like

'We don't remember days, we remember moments.'
 Pevase

'Even if happiness forgets you a little bit, never completely forget about it!' Jacques Prevert

From Sophie Baggs. Send us quotes you like!

Mythtery of Lyme Disease



Whatever illness a patient is suffering from, a correct diagnosis is important, to ensure appropriate treatment or management of the illness. When a diagnosis of ME/CFS is considered, other illnesses also have to be excluded.

You may have heard that a number of cases previously thought to be ME/CFS may actually be cases of Lyme Disease, a tick-borne infection, since symptoms are similar - though a distinctive rash with a target-like appearance is also typical of Lyme and can point to that diagnosis. However, some of the doctors in the ME world have cautioned that there is, at the moment, over-diagnosis of Lyme Disease going on in some places, which worries the patient unnecessarily, results in treatment that is not needed, and in a general 'scare' amongst ME patients. Concerns about this phenomenon have been expressed by microbiologists, so we thought you might like some information on Lyme Disease.

Lyme Disease is passed to humans from ticks that attach themselves to the human body to feed. For a person to become infected, the tick itself has to have been infected first, and the person's immune system needs to be vulnerable to it. The infection is bacterial in nature, not viral, and is therefore treated with antibiotics.

We are informed that there are two tests for Lyme Disease. There is the ELISA test, an initial screening test which does not always give the correct result, and the Western Blot, which has to be used as a follow-up test to confirm diagnosis.

Once diagnosis is confirmed, suitable antibiotics should be given. However, Dr Darrel Ho-Yen – an international Lyme Disease expert - explains that

long-term antibiotics do not help. If antibiotics have not cleared the infection, the management of the illness is essentially the same as for ME, giving one's immune system the best chance of coping with the infection.

Dr Ho-Yen also explains that in Scotland, and probably in Britain as a whole, the bacterial strain of *Borrelia burgdorferi sensu stricto* is more common than *Borrelia burgdorferi*. American doctors and websites are therefore often dealing with different strains of bacteria from those prevalent in Europe and the UK and should you find information on the internet from US sources, they may not be strictly relevant to the UK.

how likely are you to have contracted Lyme Disease?

A new book on Lyme Disease called *Ticks, your pets, your family and you* by Alison Blackwell, George Henry and Darrel Ho-Yen explains that a tick needs to attach itself to the body and feed for quite some time.

The authors write: 'In Britain, the micro-organism causing Lyme disease is carried by our most widespread tick – the sheep tick'. Despite its name, 'the sheep tick feeds on deer, cattle, sheep and many smaller mammals in forests, woodland, damp pastures and moorland.'

For you to get Lyme Disease from the tick, it has to be a tick that is already infected. Not all ticks are infected; a survey by the Institute of Virology at Oxford found that about one in three ticks were infected with the spirochete causing Lyme Disease.

Infections only arise if

- the tick's habitat is invaded at the right season
- the tick is infected
- the human is susceptible to infection
- the human receives an 'infectious dose'

'The risk of infection depends on the length of infected tick attachment: [if it remains attached to the body for] under 24 hours there is little risk; 48 hours, 50% risk; 72 hours, almost certain infection.'

Ticks found attached to the body should be promptly removed (they are very firmly attached) and this is best done with a tweezers rather than the nails. Most of the workers at risk from ticks eg farmers, vets, gamekeepers, shepherds etc 'know what to do when they see an immobile black spot fastened onto their skin!'

Explained

Just visiting an area where ticks are present is not a 'risk factor' in itself. Being bitten, even several times, does not necessarily result in infection, and most people who live in areas where tick bites are 'a part of life' do not get Lyme Disease.

How to Remove a Tick

Ticks should be removed from the body promptly, but, more importantly, correctly.

Use tweezers, not finger nails.

Lay the tweezers firmly on the skin close to the tick's mouth parts

Grasp the tick and pull it up and out steadily without twisting

Clean the wound

Watch the wound over subsequent days

treatment

Antibiotics that are useful in Lyme Disease are listed as doxycycline, amoxicillin, ceftriaxone or cefotaxime. However, if someone has penicillin allergy, then erythromycin or clarithromycin may be used. For late disease, oral antibiotics may not be successful and 'parenteral' treatment may be needed (given directly into muscle or into the bloodstream).

Symptoms recur in as many as 50% of patients despite antibiotic treatment, although these are greatly reduced in duration and severity and the prognosis is often good. Some patients may need monitoring for months or years, depending on severity of symptoms.

where do ticks live and how can you avoid infection?

Ticks live in deer parks, forests and in other typical environments for countryside recreations such as hill walking (chance would be a fine thing, we hear you say). To avoid being bitten it's best to keep to established paths and cover up, particularly the lower parts of the body.

and finally ...

The authors point out that worry depresses the immune system! Their message is that worrying overmuch about infection makes one more susceptible to it: in areas of high risk, one should take sensible precautions and inspect the skin for ticks, but try not to be over-anxious; anyone at low risk one should not worry.

Our Research

a call for more volunteers



We recently committed our £14,000 Research Fund to a specially designed study at the University of Dundee.

We sent individual invitations to all our members aged 9-18 in the following postcodes, inviting them to take part: DD (Dundee), KY (Kirkcaldy), ED (Edinburgh), G (Glasgow), AB (Aberdeen), PH (Perth), IV (Inverness), FK (Falkirk), ML Midlothian), DG (Dumfries), TD (South East Scotland).

Many thanks to all who have already joined in. Some families have journeyed from as far afield as Wales! We realise that travelling is exhausting and expensive and we are very grateful; home visits are not possible, since within minutes of a blood sample being taken, Dr Kennedy has it in the laboratory and is working on it.

The study is an investigation into biochemical and blood flow aspects of ME/CFS in children and young people. Led by Dr Gwen Kennedy of the Vascular Diseases Research Unit at the University of Dundee, it is the first to investigate biomedical markers in children. The UK Chief Medical Officer's Working Group Report noted that research in children with ME/CFS was an urgent priority. The team are looking for further volunteers in order to complete its work. Please contact the Trust for further details.

This study is funded by MERGE, The Young ME Sufferers Trust and Search ME.

GP Line

our own experience

Access to a GP's advice any time, anywhere, even abroad or on Christmas Day? We are pleased to report that our own experience of GP Line (in the middle of the night!) was extremely positive. There was a real person at the other end of the line, who was most efficient and kind and took full details; the GP called back when they said he would, and spent a long time advising, reassuring and answering questions.

If you'd like to register for the special rate of £50 per year, negotiated by the Trust with GP Line, please call us. There is no limit to how often you can use GP Line, or how many topics you may discuss. All doctors are qualified, practising family GPs. They are there to advise you at home, on holiday, in the night, even abroad, and will spend as much time as you need. Friends and relations can also get our special rate.

'Isn't it so wrong...'

flora is a normal mum whose daughter has me

Hi Jane, Flora - Samantha's mum - here. I have just sat through some of the Westminster conference DVD and feel I have to contact you. Thank you so much for your contribution. What an excellent, informative and 'easy to understand' talk.

I have to admit to sitting here in tears; what you describe is absolutely spot on, our education authority/system and the medical profession should be ashamed of themselves for putting so many of our dear children through this nightmare.

As you know, we have been to hell and back over the past 6 years with Sam's secondary school and our local education authority. Fortunately I found you and educated myself about this illness in children via your knowledge and research.

I am the strong one in the household and therefore did what I knew was correct and did not force Samantha into school, much to friends, family, husband, doctor and the school and education authority's disgust.

Sam wasn't diagnosed for years and that was a tough time because I was, I know, looked on as neurotic, paranoid and an older mum; nevertheless a mum knows her child and I knew Samantha was ill ... what with, I didn't know, but that wasn't the issue.

SHE WAS ILL and needed to be believed and helped. The only one who seemed to believe and try to help

her was me, her first home tutor, her junior school head and a very special school matron.

We are where we are today due to sheer guts, determination, heartache and belief in our child. A weaker person, and there are many who would not have persisted as I did. I have had to shout, insist and appear to be an ogre for the sake of our daughter. It's not a nice feeling but had to be done. I feel so sad for those children who don't have such forceful parents. What happens to their health scares me.

I am thrilled you are setting up online teaching about the illness for teachers. I intend to invite Samantha's secondary headteacher to our house to see your section of the conference DVD. She is setting up a meeting for Sam and myself with the SENCO county news editor so I would very much like her/him to come as well. They know that if the LEA don't take this on board, I will re-open the case against the school and the LEA re discrimination, negligence and, as advised by my barrister, the human rights issues. Isn't it so wrong that things can get to this?

But it doesn't have to. As a former head teacher, our Executive Director can help parents and schools.

We suggest you give photocopies of the page opposite to your home tutor and school and ask them to take advantage of this offer. Your home tutor could watch at home with you.

Review : Zoe's Win by Jane Colby published by Dome Vision

Zoe is a star pupil in Physical Education and when she starts to lose her abilities no-one around her, as well as herself, understands. The reader knows why and cringes when Zoe is told to 'Pull yourself together, girl! You're always fussing about something. There's nothing wrong with you. You can't win if you don't try.' We feel empathy towards the people around Zoe who are helpless in making Zoe better, particularly her mother who is scared on her behalf.

Part Two of Zoe's Win is aimed at the teacher who teaches a child who lives with ME. It is direct, informative and simple to understand, and the

inclusion of children's poetry about their ME experience is an apt touch to bring the teacher closer to understanding a child who lives with ME.

As a teacher I would have found this book beneficial if I had a child in my class with ME and also if I had not. Because any professional dealing with children and their needs has to understand as much as possible about the health, welfare and education of children, and what can go wrong.

From a review for Sheffield ME Group by teacher Joanne, who dedicated it to her mother.

£7.95 inc p&p. Cheques payable to Dome Vision may be sent with orders to Tymes Trust for processing.

Remember

Earlier this year we announced a significant expansion of the Tymes Trust/Nisai Education Partnership. There are now up to 2000 free interactive online home learning places for over 16s in the Nisai Virtual Academy. For information, phone 020 8424 8475 and ask for Preya or Andy. Explain that you are registered with Tymes Trust. If you are under 16, you can ask them about funding by your Local Education Authority.

 nisai education





Healthy Results

is it possible to raise the educational achievement of children with ME and support their health, both at the same time?

Aiming to help children with ME get better whilst also achieving top grades seems rather like asking for the moon.

The answer lies in the nature of the illness itself. ME causes more long term sickness absence than any other illness – pupils are physically fragile and lowered blood flow to the brain affects their memory and concentration. Consequently, much of the time they could be learning is spent recovering at home, and much of the time they are in school they cannot concentrate properly.

Online Training for teachers and parents in supporting pupils with ME/CFS

Provided by The Young ME Sufferers Trust in partnership with Nisai Education

On September 19th a pilot seminar was delivered live by former Head Teacher Jane Colby, Executive Director of the Trust, a member of the Chief Medical Officer's Working Group on CFS/ME and a major contributor to the Department of Health Report of 2002. You can now view this training seminar at a substantial discount.

You may watch the session at a time of your choosing, alone or with a group. As a result of the initial seminar, teachers may notice an immediate impact on their confidence in tackling this difficult issue. Take part in further sessions and you may also notice a long-term improvement in the grades that the school achieves from these pupils.

If you wish, you may register for a live interactive session in 2007, in which the special educational needs of children with ME will be addressed in further detail.

Besides the benefits mentioned above, it's worth remembering that one teacher has already won an award for supporting a pupil with ME after studying with Jane, and was subsequently promoted to Tuition Manager.

Parents may also like to know that one pupil won entry to Cambridge University despite being bedridden with ME since the age of 10 for many of his years of education. And he did this without becoming worse - he improved.

Work with these factors, rather than struggle against them, and you not only reduce stress on the child and minimise misunderstandings between families and teachers, you focus on the positive - on what can be achieved, rather than on what can't.

The good news is that educating a child who is recovering from ME is not rocket science, but you do need to know the basic tricks - how to work with the illness, not against it.

The Trust is working with the Department for Education and Skills on examples of good practice.

In this seminar Jane covered the following topics

The nature of ME/CFS and its neurological effects on brain and body

How the illness affects life, learning patterns and capability

How to meet the school's Duty of Care and deliver the child's educational rights

Adjusting educational provision in order to avoid further damage

To watch this session go to www.tymestrust.org and follow the instructions.

Further information for teachers

There are an estimated 25,000 children in the UK suffering from ME/CFS, which is the biggest cause of long-term medical absence in schools; 90% of calls to the Trust's Advice Line concern difficulties with education, which is cited by paediatricians as a key cause of relapse.

Cases often appear in clusters, so if you have one case you're likely to have more and it may be difficult to understand how you can best support these students.

Teachers may wish to attend the Trust's March 2007 education event to be hosted by Lord Clement-Jones in the House of Lords. Members of the Tymes Trust Professionals List will automatically be invited.

Questions? Please call 01245 401080 or email us using the Contact Form at www.tymestrust.org

The Gibson Inquiry



Dr Ian Gibson, Labour MP for Norwich North, has been Dean of Biology at East Anglia, head of a cancer research team, and been given a ‘Champion’ award by Macmillan Cancer Relief. His aim is for the Inquiry to assess the progress of scientific research on ME on behalf of ME patients and researchers alike.

On addressing the Westminster Conference

I am indeed very flattered to be here today amongst so many distinguished speakers and activists who have been campaigning on this issue far longer than I have.

On the history behind the Inquiry

The Chief Medical Officer came out three years ago with the Report into CFS/ME and it was an important step to this extent – it recognised the seriousness of the condition. I think it’s time to evaluate how far we’ve come in understanding the condition since then.

On events that sparked the Inquiry

Various constituents had come to see me. They brought Professor Hooper to see me as well, and I’ve had other groups come to my constituency office in Norwich. Whether I’ve got political antennae or whatever, I said we needed to raise the profile of ME and settle some of the arguments if that is possible. I thought I would do it in an independent way. This is a major problem involving some quarter of a million people and it does cost the exchequer billions of pounds.

On his personal aims for the Inquiry

To stimulate public debate and interest in ME/CFS and act as a catalyst for increased funding into research which I hope will one day lead to a cure. That may be pious stuff, but that’s my intention.

On prejudice

Where there is prejudice we’ll try to eradicate it with good sound sense, and science and information, so that people who want to do that research get the backing and support that they need.

On the membership of the Committee

I had to ensure that it covered a range of people from both Houses of Parliament, the Lords and the Commons, and that it satisfied to some extent - it’ll never satisfy everybody - the broad range of opinion that there is.

On the challenge it poses

Perhaps I like difficult challenges and we shouldn’t run away from it.

If Parliament’s a place that can make things better, so it should be.

On the controversy

I come from a scientific background and I’ve never met two scientists who ever agree about the interpretation of each other’s data. That’s how things move on – that we encourage that kind of debate.

On the evidence the Committee has received

The Group has had a lot of written evidence from sufferers, charities, research groups and other organisations and individuals. We’re going to have oral hearings [these are now complete]. This will all be the basis of a final report¹.

On the seriousness of ME

People are starting from the basis that they know it’s for real, that we’re not just messing about here, that this is just as serious as cancer or any other problems.

On the size of the undertaking

There is a huge stack of evidence and it is a lot of work, but it *is* being done. It’s been quite mind-opening for people on the Committee.

On the value of patient groups

Departments of Government are learning that they don’t have the ultimate knowledge, that people are who are going through the condition know much more about what it’s like, and what needs to be done, than civil servants sitting in Whitehall.

Final thoughts

I don’t think we’ll have all the answers but let’s hope we have enough answers to move it forward.

To see all the speeches in full, watch the complete DVD of the Westminster Conference, available from Invest-in-ME (IiME) by following the *Order The DVD* link at www.investinme.org.

¹ The Gibson Inquiry’s report is expected in the Autumn. Read the Trust’s evidence at www.tymestrust.org/tymespublications.htm.

You Tell Us



I hope this email finds you well, and that the weather is a bit better than it is up in soggy, cold Halifax!

Studying with the Open University has gone incredibly well over the past year, and I've now had scores back for the first 85% of the course, and waiting on the final 15%. With regards to education and support, the OU has been

undoubtedly the best. It's made me realise exactly what a struggle we were having when I had my relapse back in March 2000 and were trying to persuade my college to give support with my A-levels. A DSA award has provided me with a fully supportive chair, and a computer desk at the right height, as well as other equipment to assist me - the list is too long for me to even remember!

The tutor was wonderful, and any extensions I needed or special considerations for my exam-like assignment were granted with no problems at all.

I just hope that one day all schools and colleges will accept ME as a real and serious illness, and provide the necessary support to get young students through education, rather than us all having to wait until we can study with a supportive institution such as the OU!

Best wishes, Sarah Mills

To study with the OU, you don't need any prior qualifications. Just like your friends at uni, you could have a degree too.

Sir David Attenborough OM FRS, has described David Loxley-Blount's photography as 'excellent'.

Mum Jan writes: 'David Burrows MP judged the May Day Fair, and David's frog won!' As Mr Burrows wrote: 'It seems you are a multi-talented young man!' To read about David's other exploits, see page 9.



*Frog, by David Loxley-Blount
(C) DJ Loxley-Blount & open2i.co.uk*

Whenever you write or email us, don't forget to say if you would like us to quote you in Vision. Send a photo too if you can!

THE Question

Fundraising - what's your view?

In each issue of Vision we ask your views on a particular topic. As you know, whenever we seek our readers' views, we act on what you tell us.

In this issue we've shown various fundraising (fun-raising?) antics that people have been up to. To keep services running, all organisations need to fundraise - and what creative ideas you come up with to help the cause - on your own without us asking! (Which is nice - we don't like asking.)

We generally keep the totals to ourselves, in case someone starts comparing and feeling their total wasn't as big as they'd like. But of course, every little helps. The smallest coin collections add up to grand ones. The Marathon total (page 10) got so big in the end because smaller donations accumulated. The collection by St Mary's Church in Redbourn and the Farmer's Market each came to £150 (our thanks to Jonathan Goodchild and David Hampton) and the Trolleyboys' gig totalled £342 (our thanks to Stuart Cole). You can see the photos in the last issue.

For future issues, what's your view? Is it better to print totals? Let us know using the Contact form at www.tymestrust.org or pop a note in the post - or just ring in. All views welcome.

Write to: The Question, PO Box 4347, Stock, Essex, CM4 9TE

SEB'S MANOR



What, Jodie AGAIN? She's made a take-over bid for my page. Her two names BERNARD and BRAIN got chosen for the back page teddies. Their Mystery Owner from our 26+ group is quite satisfied. He's told the bears.

Sebastian Says

I'm in charge of the prizes,
I'm in charge of the prizes!
Ner ner ner ner ner.

But most of you know that already.

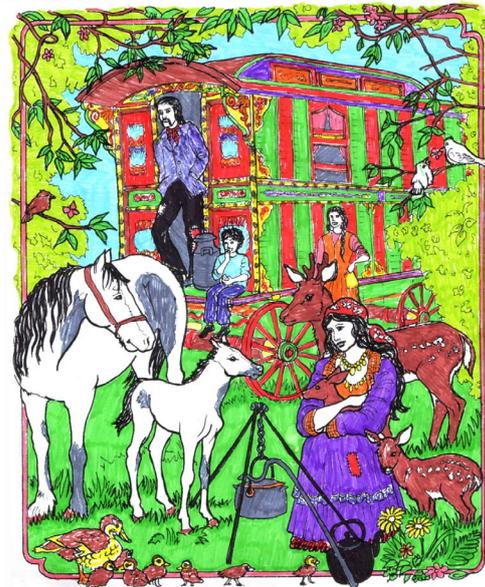
And here's the best thing - I get to choose whose pictures get published. This time I've chosen Maggs, Jade, Emma and Jodie, who've coloured in Susie's caravan. In fact, Jodie entered so many competitions I sprained my wrists rummaging in the treasure chest. Humiliating. I was so not amused.

Emma's mum Adele writes: 'Sorry it took a long time to do this, but Emma has been very poorly - she was determined to finish and return it to you.' That's the way, Emma. A little bit at a time is how to do it.

Congrats to everyone who completed the poem (you were all right) and guessed the names William, Moley and Bandit (only Jodie got them all!) Even if you aren't well enough to enter straight away, it's always worth having a go. We know that ME and deadlines don't mix, so if you deserve a prize and we've got some left, you get one!

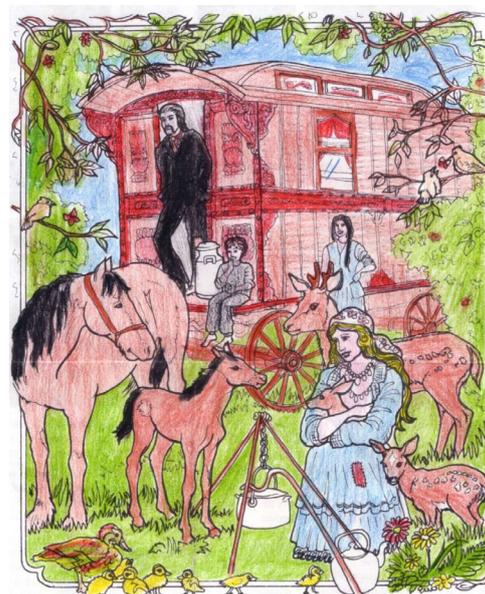
Love, Seb

PS Here's a special 'Hi!' to Emma as she's been so poorly and we want her to know we're all thinking of her. If anyone else wants to send her a card, we'll forward it for you.



Emma Gray

Maggs O-Sullivan



Jodie Halliday

Jade Smith

SEB'S COMP

Answers to last time:

The bear on the front was William - find what he was pointing at by reading the inside front cover (bottom). 'Look! A Heffalump!' said William. And in the issue before that (same place): 'Moley and Bandit review an early copy of Vision.'

Well done if you found it.

This time, you get a prize for counting the number of hearts in Susie's Young Hearts picture (in Things 4 U 2 Do). You need to look hard...

Always tell me if you want me to print your name, and say if you want my Magic Pens (they change colour) or a surprise from the Treasure Chest.

Seb's Photo Spot

Mark Lever

The winter scene photo was taken by Mark in Headley on Epsom Downs where his aunt and uncle live. I am attaching a couple of photos of Mark playing cricket. Mark plays and trains for cricket once a week during the summer months by pacing himself. He is an excellent bowler and is now working on his batting.



When you consider that he was hospitalised at the age of 3 with post-viral paralysis and here we are 13 years later!

Rosemary/Mark Lever

*Would you like to be in my Photo Spot?
Send me some photos and some stuff about you.*

Jodie's sent me lots of stuff as well as Susie's caravan: names for the bears, a cloud collage to illustrate Sazza's poem, the right words to the 'Company' poem, and pictures of Me Me Me! I've sent her a host of surprises from my Treasure Chest. She must have a collection by now.

How many pictures are YOU going to send me this time?



Cloud Drifter



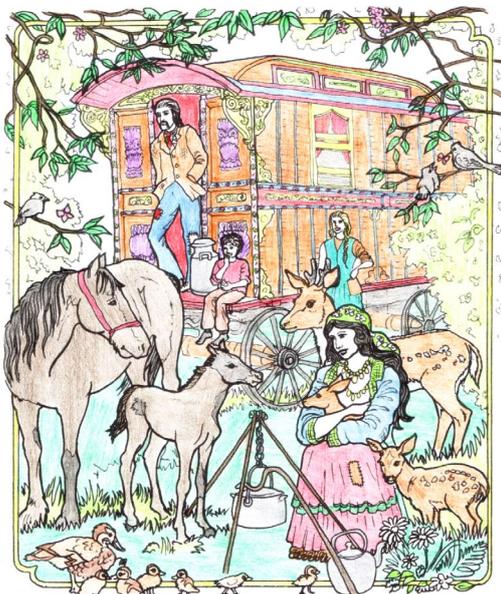
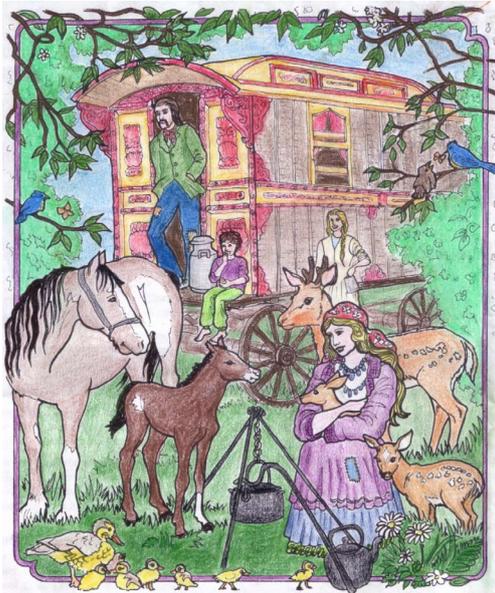
Me scuba diving



Me on the beach



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



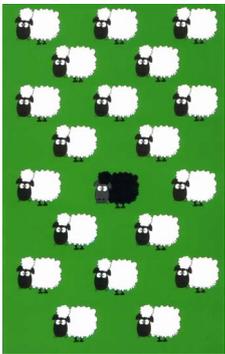
A letter from ...

I feel that I am now well and that someone else should get my copy of Vision. Thank you so much to everyone at Tymes Trust who have helped me throughout the years, you have been an endless support to me and my family and I can't thank you enough. I hope everything goes well in the future.

Lots of love and best wishes

Kirsty Watts

Xxx



20Q Returns!

Dear Tymes Trust

Thank you for lending me the 20 questions game. I'm sorry I've had it for so long! We've all had a lot of fun using it. It's amazing how something so small is so good at that game!

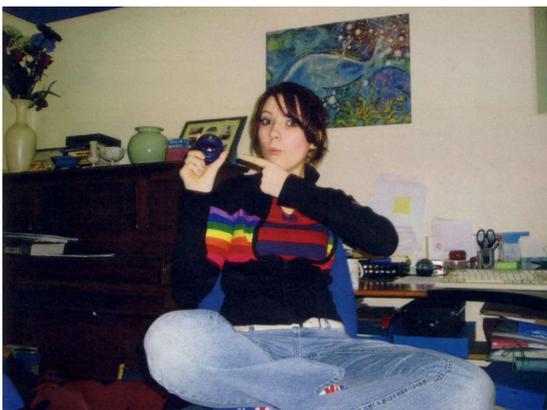
Not that it managed to win all the time, but it can get some very difficult ones! For some reason it couldn't get itself, which we found quite funny ☺ You asked for some pictures of us playing with it, which I have also sent. We had a small collection and the cheque is enclosed.

Thanks again for lending it to me, we had a great time with it. It's helped keep me sane over my exams!

Hope you're all having a nice summer.

Katherine Langford

Could it be your turn to borrow Mark's 20Q thinking robot (it has decided it wants to be called Melvin)? Mark has it all ready to go out again to another lucky family. It has a brain that's smaller than your hand! You can play it in bed, on the sofa, in the hammock - anywhere. Melvin can keep you company when there's no-one around to talk to. Just send your request to 'Melvin' at the Trust's address. (A contribution to the new postal costs would be helpful!)



Just send your request to 'Melvin' at the Trust's address. (A contribution to the new postal costs would be helpful!)



I'd like to renew my subscription to 26+. Use the extra £10 for birthday cards, Christmas cards, or - if someone is having a very bad time - Thinking of You cards!



Mary Lee

You are welcome to stay with us as you get older or are feeling better! We just ask for a small contribution if you are over 26.

Kat (top) and her friend Beth (below and left)





Out and About with Kinnerton

Our pup arrived the day before our holiday. He is named Kinnerton, after the dairy-free chocolate that Edward can eat. We had fun posing him in teashops, and we had some odd glances! He was also allowed to play monopoly in the caravan. Edward is developing an interest in photography, like his Dad. We had a good holiday - we took each day gently and had plenty of fresh air. Many thanks for sending Kinnerton; he has settled in well. We have a week booked in North Wales, where we will visit friends, Harlech Castle and the pottery. Kinnerton has already packed his bucket and spade!

by the statue of st cuthbert and with edward outside the priory, holy island



by the big fountain in alwnick gardens



by the bridge at berwick upon tweed

soaking up the sun at the caravan park



playing monopoly with cadbury and friends in the caravan



at alwnick castle in front of the statue



posing on a cannon at banburgh castle



homing in on a cream scone at banburgh castle

oh no! about to demolish daddy's cream cake! chainbridge honey farm

overdone it! daddy shocked at having lost his treat



photos by edward and daddy kimberley



at hadrians wall, vandalanda fort, on the way home

Sally's Open Day



Looking back on a glorious summer day at Westlands Garden and Nursery...

If you would like a personal invitation to our restful Open Day 2007 in Sally's beautiful garden and tea room (plenty of seats and surely the best home-made cakes in Essex!) let us know now and we'll put you on the list. We all thank Keith, Sally, James and Lucy Player for making the day one to remember, and £700 was raised for the Trust's work.



It was great to see Dr Betty Dowsett, Sky News presenter Gordon Radley, new volunteer Anthony Welsh and all the members and friends who came.

www.westlandsnursery.co.uk



Hello Everyone!

I thought it time that I put pen to paper now that I've had a few days to recover from my journey to Scarborough. As you can see from the photo I've made some new friends, Patchy and Fudge, and my new owner, Jasmin, lets me sit in her wheelchair.

Jasmin is 13 and has severe ME and is spending all her time in bed now which makes her very sad but I have come here to cheer her up. I was so thrilled when I arrived and when Jasmin's Mum took me out of the envelope I took my first breath of the lovely sea air.

I sit on Jasmin's bed and help look after her and tell people to go away when she has had enough. I'm really enjoying my new life in Scarborough and Jasmin is so kind to me and gives me lots of cuddles - it's great.



Thank you so much for sending me here, I couldn't think of a better place to be than with Jasmin.

Love from Rusty Wakeford xxxxx



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