

The Young ME Sufferers Trust
November/December 2004
£2-95

Vision

YOUNG HEARTS DAY

Terry Waite launches
Young Hearts at
Warwick Castle

MEET OUR NEW PATRONS

Earl Howe
Shirley Conran OBE

NEW RESEARCH INTO ME IN CHILDREN

Funded by The
Young ME Sufferers
Trust and MERGE

THE BRIEF

First in a series of
information pullouts
by Jane Colby



SUPPORTED BY JADE'S DREAM APPEAL

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THE YOUNG ME SUFFERERS TRUST

Registered Charity Number 1080985

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Our Patrons



Lord Clement-
Jones CBE



Earl Howe



Shirley
Conran OBE



Lady Elizabeth
Anson

VISION: THE PROJECT

This – our best kept secret! – is the pilot issue of *Vision*, part of a wider and far-reaching initiative by the Young ME Sufferers Trust.

As all good visions should, it looks towards a brighter future with increased understanding of ME and better care for all. It brings together ideas suggested to us by you, and by our volunteers, supporters and patrons, who have made, and will continue to make, personal contributions.

The project has four main aspects. One is to ensure that all our reports, information packs – indeed, all our publications – are made available *completely free of charge* on demand, at any time of the day or night, via our website at www.tymestrust.org

The process is already well underway. In *The Brief* (centre pullout) is a list of our publications already available online. By the time you read this, there will be more. If you are not online yourself, you can ask your local library to print them or contact our Advice Line for other arrangements.

Another key aspect of the project is to step up our campaigning on issues vital to children with ME and to report back to you on progress.

Yet another is to embark upon a biomedical research study that could even contribute to the development of a treatment.

And then there is *Vision* itself, carrying advice, information and shared experience, to which you can contribute. Thank you to everyone who has let us know the kind of features you find most useful and enjoyable. We have incorporated as many as possible.

June 2005 marks the 20th anniversary of the day when our Executive Director Jane Colby, then a Head Teacher, was struck with severe ME herself and had to leave teaching to rebuild her health.

In the last twenty years Jane has written books and specialist articles on ME, working with government agencies, schools, Local Education

Authorities, doctors and researchers and also with many ME organisations along the way. She has now been asked to provide a regular centre-page pullout that can be stored in a binder for reference. The first is in this issue.

Initially supported by Jade's Dream Appeal, the publication of *Vision* links in with the launch on November 29th of the book *Young Hearts* in Warwick Castle.

We have named this day 'Young Hearts Day' and every year it will be commemorated by the Trust. We are honoured that Terry Waite, former Envoy to the Archbishop of Canterbury, chose to be with us for the first ever Young Hearts Day in order to launch the book.



A beautiful collection of poems by children and young people with ME, *Young Hearts* was produced to raise awareness of ME in the young.



Jade Louise Scarrott was only fourteen when a random accident on our roads took her from us, but the book she had started with us has been completed in her memory.

The heart of a child is often the best source of wisdom for adults. Jade's dream has become reality with the launch of this book and is carried on into the future with Jade's Dream Appeal and our *Vision* project.



Keith Harley
Chair of Trustees

Meet Our New Patrons

I am delighted to welcome Freddie, Earl Howe and Shirley Conran as new patrons of the Trust.

I have worked closely for many years with Freddie Howe in his capacity as the Conservative health spokesman in the House of Lords and he is tireless champion of good causes.

Through her books and by example, authoress Shirley Conran (most famous quote: 'Life's too short to stuff a mushroom!') is a dynamic inspiration to many women both in the UK and worldwide.

Both will make a real difference to Tymes Trust.

Lord Clement-Jones
CBE
Founder Patron



Earl Howe

Shadow Health Minister
(Lords)
Shadow Minister for Children
and Families

I feel very honoured to have been asked to be a Patron of The Young ME Sufferers Trust. In my opinion there is no other organisation in the country that

so effectively champions the needs of young people stricken with ME or that provides them with such fantastic support.

I take my hat off to all at Tymes Trust and wish them continuing success in the invaluable work that they do for young ME sufferers and their families.

Freddie



Shirley Conran OBE

In case you've sometimes wondered why there are so many 'grey suits' in these pages...as I see it, this magazine has two main jobs. One is to keep you in touch with one another, the other is to make things better for you.

The way to improve a situation such as ME awareness is by campaigning. A campaign might consist of two parts. The first might be, for example, a petition signed by thousands of people, asking for funding for specialist nurses to help care for children with severe ME at home, to be presented to someone who can help, such as the Chancellor of the Exchequer. He is in charge of Britain's housekeeping money.

The second part of a campaign might be to approach someone famous and influential, someone in the public eye who is respected and listened to by the media and the Government. This isn't easy because they are very busy people.

High profile people often have influence – the ability to reach and persuade the right people – such as the Prime Minister, who supports the work of The Young ME Sufferers Trust – to improve things for young ME sufferers.

I know how effective this can be because for six years I have run a charity with only twenty volunteers which has aimed to teach the whole country the importance of work-life balance (even more important if you have ME, as I do).

So every time you see those pictures of grey suits, remember that the wearers are soldiers in an army that is fighting for YOU!

Shirley Conran

PS Jane Colby is of course the Army's General.

New ME Guidelines for Paediatricians

An exclusive for *Vision* by Linda Haines, Principal Research Officer, Royal College of Paediatrics and Child Health

A new guideline developed specifically for doctors looking after children and young people with CFS/ME and produced by The Royal College of Paediatrics and Child Health will help doctors understand more about the condition so that they can support young CFS/ME sufferers and their families.

We are now approaching the final stages of this process. The guideline has been written by a group of experts who have a lot of experience of looking after young people with CFS/ME, after considering all the available research evidence. There will be a separate information leaflet for young patients.

Once the final publication is ready to be launched, the guideline and the leaflet will be sent to all of the members of the College which means that most of the paediatricians in the UK will get a copy and both the guideline (which will run to over 100 pages) and the leaflet will also be available on the RCPCH web-site at www.rcpch.ac.uk

The guideline will cover many different areas including:

- * how to diagnose CFS/ME
- * how to tell young people they have CFS/ME
- * advice on how to control the amount of activity you do each day
- * some methods which might help the symptoms common to the condition, for example, helping with sleep problems
- * what can be done for young people who are severely ill with CFS/ME
- * what the doctor could do to help young people who miss school because of their illness

Jane Colby was a member of the Delphi Group (first specialist consultation phase) and the Trust was a stakeholder in the end-stage refinement process. The Trust will produce a commentary and analysis of the final publication.

In The Spotlight: The TRUST'S Position On...ME Clinics

The Government wants the 'Expert Patient' philosophy to affect all areas of the NHS. We believe that patient autonomy is needed in ME/CFS services. With no cure available, patients should be supported in caring for themselves in their own way, with support from their GP and/or consultant.

As part of our investigation into your own views, Amy Bakewell wrote: 'I would like recognition from the entire medical profession and some national ME charities that Graded Exercise Therapy (GET) and/or Cognitive Behaviour Therapy (CBT) for some people is not going to be the slightest bit helpful.

'I've tried the approach twice (it's the only thing I've been offered) for 6 months the

first time and for 5 months the second. It was a resounding failure both times. In fact it was detrimental – months of increased pain and exhaustion and then you crash. Yet in terms of official reports I don't see any evidence of *my* experiences being acknowledged at all. It's infuriating and I could go on and on about it. For example, some charities seem to like saying how these treatments can be helpful. Their present acceptance of the official line is very misleading.'

Patients should not be pressurised. As different forms of 'chronic fatigue' can now become trapped under the same CFS umbrella, your own judgement should be respected over what is best *for you*.

What you think



Thank you so much for the lovely birthday card you recently sent.

I really appreciate the time and effort it takes to handwrite them!

Victoria Flute

Thank you *so* much for choosing my poem 'Reliving a Memory' to be included in *Young Hearts*. It was a brilliant surprise to receive your letter, and made my day.

The poem was first published in the magazine – that was exciting enough! I'm so chuffed to be included in the book. I had thought of sending something in especially, but I haven't had the brain for poetry writing for a while. I was very saddened to hear what happened to Jade and I'm glad you're doing the book in her memory.

I also want to thank you for showing my competition entry – 'Things That Make Me Smile' – in the magazine. I think being mentioned in the magazine should be added to them!

Anna Sheppard



So uplifting to read a magazine with an intelligent, sensible understanding of the illness and with news of effective campaigning. 'Making a Difference' spoke to me in a helpful way. 'Be pro-active, not just reactive' seemed like something I should try to do.

Catriona Courtier

Thank you for your many encouraging comments about Tymes Magazine. We hope you will find Vision similarly uplifting, seriously helpful – and fun.



From receiving her first copy four years ago, Jade was comforted to know that she wasn't alone with this debilitating illness. It is from *Tymes Magazine* that her love of poetry blossomed especially when her poem 'Light What Light' was printed.'

Karen Scarrott

I'd really like to say a huge thank you for all the work you have done for young ME people and for all the support you have offered me over the years.

It's been great knowing someone is there to help or give advice if I want it, and reading *Tymes Magazine* has been interesting and enjoyable. I've much appreciated all the birthday cards as well!

Long may your organisation continue to help young people who so desperately need it, and to campaign on their behalf.

Catie Jenkins

COMPUTER REPORT

It was nice to see everyone again earlier this year at Sally's Garden Open Day for the Trust. Back in 2002, I was one of the lucky winners chosen to receive a computer from The Young ME Sufferers Trust at the House of Lords.

The computer has been so useful. Since then I managed to complete all my GCSE coursework at home, because of the computer!

I use the Internet a lot and enjoy sending and receiving email. It would be great if everyone who is too ill to attend school could own their own computer, to help keep them in touch with the outside world.

Jessica Quilter



Lord Clement-Jones with the lucky recipients Jessica Quilter (left), Victoria Travis and Jacob Essex on the House of Lords Terrace

GETTING THERE

After nearly six years of battling with ME I am starting to rebuild my strength. I turned 19 in October, I have started to work two days a week and have also taken on a home-learning computer course.

I have done so many things that would seem small to any 'normal' person but to me they were huge. For example, working two days *and* going to a cricket match, which was the best! Very tiring but I managed it; a couple of years ago I wouldn't have imagined doing that.

It is going to take a long time to recover fully, if it ever happens, but I will get there eventually. ME is life altering. I just want other people who are out there suffering from this illness to know that there is always hope.

Thanks for my birthday card and my invitation to let you know how I am getting on.

Charlotte Bicknell

Have you answered your 2004 invitation yet? There's still time. Every story is welcome, whatever your situation, however well or ill you are.

IT'S OUR TURN TO THANK YOU : PLEASE KEEP IT UP!

Buying your CDs, DVDs, books etc through our website has brought our recent total from Amazon to nearly £200 from this facility. And it doesn't cost you any more than if you went there directly!

So when you're spending gift money, please continue to remember us. There are no extra forms to fill in. Just go to www.tymestrust.org and click on the link.

All monies go to services for children and young people with ME as our work is entirely voluntary.

DO FAMILIES WANT CARE IN THE HOME?

The Young ME Sufferers Trust has been awarded a grant from the Local Network Fund for Children and Young People under the programme 'Children's Voices' to study what young people and their families in our home area of Essex want from the Government's new money for ME/CFS services.

We began by seeking a 'thumbnail sketch' of the views of families throughout the country on many issues, to compare with Essex. In the Summer we reported to you that 85% of families gave the thumbs down for the automatic involvement of psychiatrists in the care of children with ME.

Karen Scarrott, mother of Jade, has told us that she particularly wants to see care in the home for children with ME, given by specialist nurses *who would not just visit*, but give *hands-on help* to those caring for very sick youngsters.

We agreed to help her press for this service, as we had already published a statement on the very same subject. Initially, we met with her MP in Westminster and are continuing to work for specialist nursing care for those in need.

We can now reveal that 89% of families who gave us their views agree with Mrs Scarrott, that practical hands-on nursing care should be available in the home. If you have need of this, to help you care for a young person who is severely ill with ME, please let us know. We will keep your details confidential.

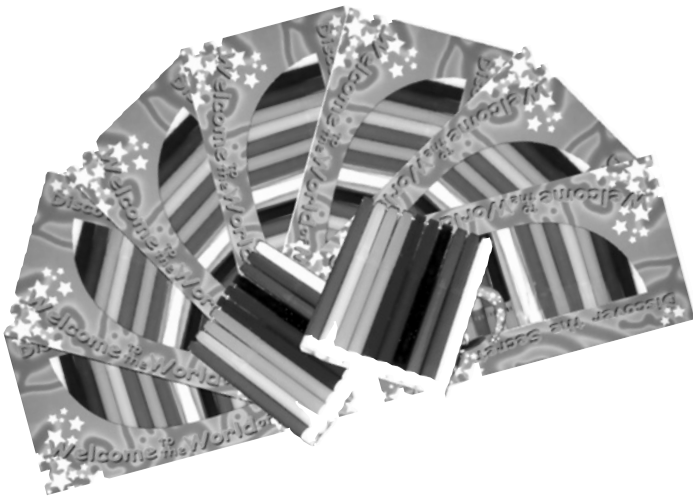


*The study continues, with Dr Nigel Hunt. If you have joined the Trust since the original green forms were sent out and you would like one to complete, please send an s.a.e. to Green Form Please!
PO Box 4347, Stock, Ingatestone, CM4 9TE.*



Dear Simon...

When we met with big-hearted Simon Selkin at the Ideal Home Exhibition in London, the result was a Great Big Box of Magic Gifts for Young People with ME, donated by William Selkin Ltd, who were key exhibitors in the gallery. To request one of Simon's gifts, we asked you to send us a postcard telling us about someone who's made you happy. We promised to print some of your messages and here is our choice.



My friend Kat Ramsay makes me happy as she's a wonderful friend, has a great sense of humour, is kind and very caring. She also 'meows' along with songs which makes everyone laugh.

Love from Vikki George, aged 19 severely affected BUT writing this myself for the first time for 3 years!

Picture © Young Hearts



I'm 16 and I would like to request a gift for my friend Beth (she's 13). She's been really amazing. She's really understanding about ME and always supportive of everything I do. She even helped with a charity event I had. She's the perfect friend for someone who has ME and I really think she deserves to have a gift. Wishing everyone lots of sunshine.

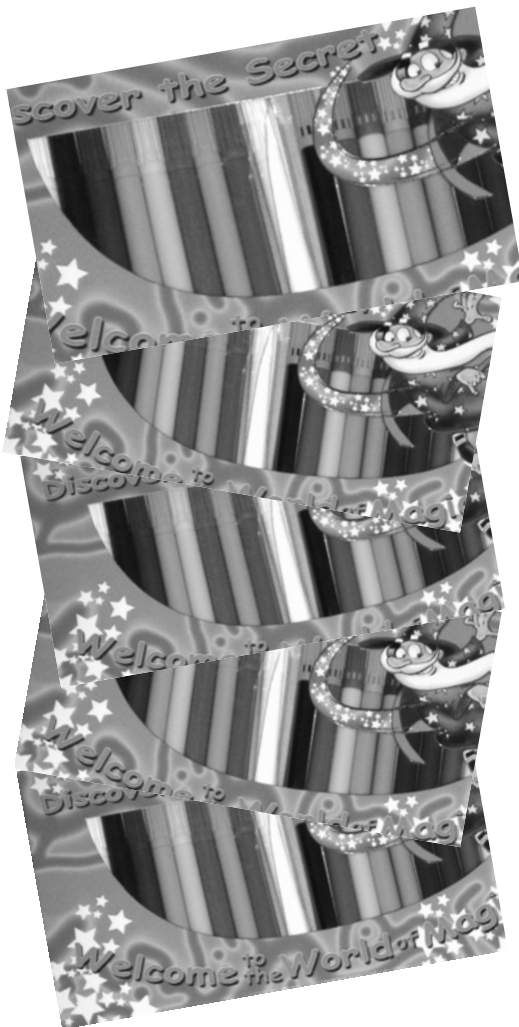
Kat Langford, 16



'I have spent the best part of 11 years in and out of hospital. I've currently been in for over a month, which is why Vikki is writing this for me. Some people take the time to write to me – it makes me happy when I hear from someone.'

Vikki George, wrote this on behalf of Kat Ramsay, aged 21 severely affected, bed-bound, tube-fed and hospitalised. Vikki says thank you to those who write – you make her life happier.

If you would like to write to Kat, send your letters to The Young ME Sufferers Trust and we will forward them on.



The person who is guaranteed to always make me smile is my friend Amy. She also has ME. She's completely bedbound in fact, but that doesn't stop her cheering me up! She rings me when I'm particularly down as well as other times too and always makes me feel happier and less alone while fighting this illness. I always love it when my phone beeps with messages from her and while I was in respite care recently, she sent me a parcel of the cutest card and a CD I'd wanted for ages – it was wonderful to come home to that surprise!

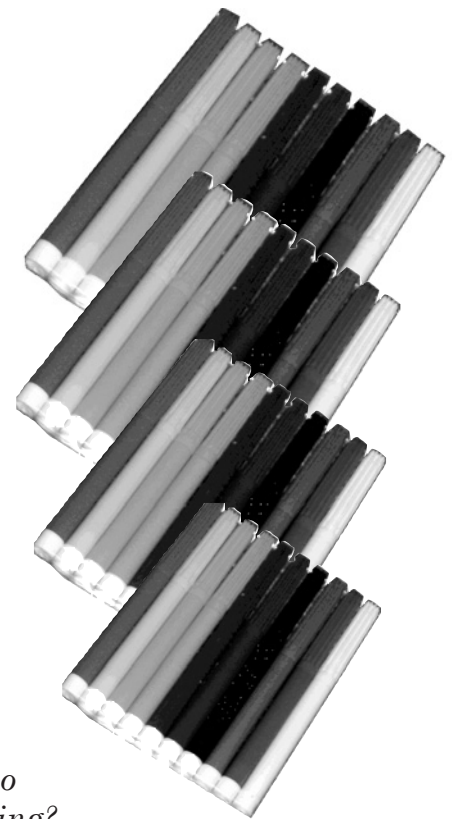
All the friends I've made while I've had ME are amazing. I wonder what I ever did without them. They are people I can tell the harsh truth about illness to, but also people I can laugh with. Some days I wake up and realise that I have the best and most understanding friends I've ever experienced in my lifetime and there were days when all that would keep me going was the knowledge that the post would come or my phone would ring, bringing friendship and support home. I've never met a more generous and thoughtful group of people.

Eleanor Ward



Could I request a gift for my very good friend Ami. She has ME and is really poorly with it. She is always so cheery and makes me smile with her lovely text messages and the surprise gifts she sends me. Big Huggles from me 2 her – thanks a lot. Loads of love and smiles.

Sarah Wilcox



Everyone who wrote in has received a gift – and we also sent one to their friends! Simon was so generous that we still have some gifts left, so if you're feeling down and aren't well enough to write, maybe your mum or dad could ask us to send you something?

Love From ...

Meet The Team



Frances Ommanney Advice Line Team Member

Background I was diagnosed with ME in 1989 having been unwell for two years, and I stopped work as TV producer/director in 1993. I found my skills and professional expertise very useful to help both myself and others with ME – they still are!

I am mother of Rupert, now 17, who was very ill with ME symptoms for three years. Recently I have taken a 6-week course (2.5 hours per week) and am now an Accredited Volunteer Tutor for the Expert Patients Programme. This meant learning to use self-management techniques, which are particularly helpful for those of us with long term chronic illnesses.

Hobbies and Interests I like talking to and being with friends, going out to meals, going to parties, the cinema and the theatre (ME permitting).

Favourites Colour – indigo blue; Tree – the oak; I haven't got a favourite book or author because I read as much as I can. I *loved* 'Lord of the Rings' (read when I was 17).

Personal Message Having to learn to live with ME has taught me how to slow down while staying alive, passionate and enthusiastic about the things and people I love. ME is a very harsh teacher in my opinion but it has enabled me to truly be there for others as indeed others have been there for me.



Mr Harley's Brilliant Bears

The time has come around for Mr Harley to make his yearly gift of Bears. Over the years he's found Benevolent Bears, Bashful Bears, Beany Bears, Beefeater Bears.... and the latest ones are Brilliant Bears because they sparkle.

Turn them around and you will find wings on their back. Their special task is to be a Guardian Angel (we're tempted to keep one around here...)

They'll hang up if they're in the mood – or should we say, hang *out*. Very laid back, these little Bears are. Ask them to hang out in your room, sparkle a bit here and there and guard you while you're asleep and they're likely to answer, 'Whatever.'

To get your Bear, write a note (or email via the form at www.tymestrust.org) telling us where the Bear will hang out.

Mr Harley says: 'I searched the city streets and shops for Brilliant Bears but could only find ten. Therefore, I shall put your requests into my top hat and draw the names of the lucky ten.'

Send your letters and emails to 'Mr H's Brilliant Bears' at the Trust's address.



CALL FOR INFORMATION : UNIVERSITY or COLLEGE

Have you been to University or College? Would you be prepared to share your experiences with other young people considering this? If so, please contact us.

Insight: Friends Can Hurt

‘Sticks and stones may break my bones, but names can never hurt me,’ so the saying goes. Really?

In a piece called ‘Why love can hurt like a broken leg’, Robin Yapp, *Daily Mail* Science Reporter, highlighted the work of Naomi Eisenburger and her team at the University of California. They found that ‘a broken heart may be as painful as a broken leg’.

It seems that suffering emotional rejection or social exclusion ‘triggers the same response in the brain as physical pain’. So when your friends ignore you and you feel upset, you’re not just being a wimp! They really are hurting you.

The team found that when people playing a video game with others thought they were being deliberately ignored, the area of the brain used to counter feelings of pain showed increased activity.

Some of the poems in *Young Hearts* explain how it feels to be ignored, so it may help your friends to understand better if they read it. We also have leaflets suggesting ways that they can help.

If you would like us to help you find new friends, write to us. A pack of six Friends’ leaflets in a plastic carry wallet cost £2.60



Picture © *Young Hearts*

From Our Partner Groups

Warwickshire Network for ME seeks the views of local young people

‘We are consulting with Rugby Primary Care Trust on the development of local ME/CFS services. We are keen to ensure that the voices of young people with ME and their families are heard.’

‘Our friendly group, based in Rugby, networks throughout Warwickshire. We aim to provide mutual support to fellow sufferers and carers and to share information on local and

national ME issues. We hold informal meetings for those able to attend but try to cater for the severely affected and housebound via newsletter, e-mail and a group contact list.

Email Duncan Cox, Network Co-ordinator, via the contact form at www.tymestrust.org

Or send a letter to the Trust addressed to Duncan.

Solihull and South Birmingham ME Support Group go online

You may like to visit the newly created website at www.ssb4.me.uk This is an independent, self supporting group for those living in the Solihull and South Birmingham area.

WITH GRATEFUL THANKS

We would like to acknowledge the kind and generous donation in memory of Dr Frank Paul by his family and friends to The Young ME Sufferers Trust. We remember Frank with affection and would like to express our heartfelt thanks and condolences.

Things 4

Does it weigh more than a duck?



Mark Colby challenges you to 20Q

What was the last question your computer asked you? I bet it was something businesslike, as in *Are you sure?* (not really, no), *It looks like you are writing a letter?* (so what if I am?) or *I am thinking of deleting everything you have been working on today.* *Continue?* (usually accompanied by a reassuring little pinging noise).

I bet it wasn't *Is it originally from the Mediterranean?* or *Can it be placed on your head?*

Have you ever played Twenty Questions? *You* think of something (a giraffe?) and *I* ask you twenty questions to find out what it is. My first question is always 'Animal, Vegetable or Mineral?' So a giraffe is 'an animal'.

My next question could be 'Does it have four legs?' (yes) and then maybe 'Is it cute?' and so on. Eventually I think I know what it is (or I run out of questions!) and I say 'Is it a zebra?' and you say 'No. Ha ha.'

Now we computer programmers are lazy. Why should I ask you questions if a computer can do it for me? Back in 1988 an American software engineer called Robin Burgener wondered how well a computer could play Twenty Questions. The cool thing he did was try to make it learn for itself. He didn't tell it 'Giraffes have four legs' - he let it ask people 'Does it have four legs?' It had to remember the answer for next time.

As more people played more games the computer learned more answers to more questions about more things. *And then it started to guess right.*

The computer was learning, but not very fast, because not many people were playing.

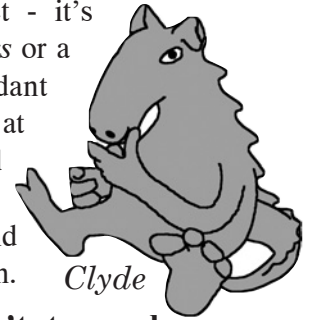
Then - in 1998 - Burgener put the computer on the web. Suddenly thousands of people were playing every day!

It learned more and more how we answer questions like 'Does it bring joy to people?' and when people tried things it didn't know about, it learned them too. This had turned from an interesting experiment in Artificial Intelligence into a way of convincing drunk people that their computer was psychic.

And you can play too. Just point your computer at www.20q.net and select *Play*.

It is trying to learn how answers change across the world so it will ask you about yourself but you don't have to answer. Just think of an object and play.

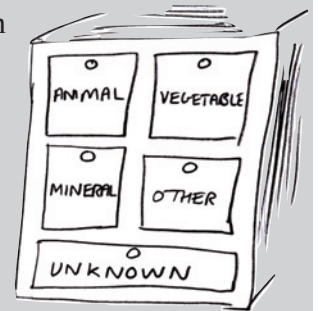
It doesn't know everything yet - it's never heard of *hobbits* or *balrogs* or a *firesuit* (that's a flame-retardant safety suit I wear in the pits at motor races) - but when I tried *headphones* it guessed in just 13 questions, it got *virus* in 14, and *beer bottle* and *dragon* in 16 each.



Happy answering, and don't try rude things or it will tell your mother.

Win a blue 20Q from Mark!

Now you can get a cut-down version of the computer and its knowledge in a tiny ball. It's not as clever as the website but it's still fun. I have a blue one to give you, if you get closest to what this object is. (If no-one does, it goes to whoever makes me laugh most.)



The web computer guessed this object in 14 questions. Can you guess it?

Animal, Vegetable, Mineral or Other? **Other!**

Do you hold it when you use it? **No.**

Is it usually colourful? **Yes.**

Can you buy it at a store? **Yes.**

Is it smaller than a loaf of bread? **Usually.**

Would you wear it on your wedding day? **No.**

Is it made of plastic? **No.**

Does it have writing on it? **Yes.**

Was it used over 100 years ago? **Yes.**

Does it provide protection? **No.**

Is it a common household object? **No.**

Can it be used more than once? **No.**

Is it smaller than a golf ball? **No.**

Is it made of metal? **No.**

I am guessing it is a ...?

Send your answers to Mark by the end of January 2005

U 2 Do

COLOURING COMPETITION – ANY AGE
MAY ENTER. PRIZES GALORE!

Picture © Young Hearts
Kerry-Ann Edge



Name: _____
Age: _____
Address: _____

To enter, ask someone to photocopy this page for you or cut it out. When you have coloured in the picture, fill in your details and send to Colouring Competition, PO Box 4347, Stock, Ingatestone, CM4 9TE

NEWS RELEASE

THE FIRST EVER BIOMEDICAL STUDY OF CHILDREN WITH ME: A UNIQUE STUDY OF BIOCHEMICAL MARKERS IN THE BLOOD OF CHILDREN WITH ME

Two ME charities, MERGE and The Young ME Sufferers Trust are delighted to announce a unique study into biochemical markers in children with ME. The investigation will be based in the Vascular Diseases Research Unit at the University of Dundee. Funding for this study has been provided by MERGE (the ME Research Group) and The Young ME Sufferers Trust (the Tymes Trust) in conjunction with the Scottish charity 'Search ME'.

ME and Children

ME (also called ME/CFS) is a disabling condition of unproven cause affecting all age groups, but it represents a substantial and widespread problem in the young. Estimates vary but there are probably around 20,000 children with ME in the UK alone, yet some doctors still refuse to recognise the problem, let alone investigate it. Attitudes are changing, however, and in a recent report, the UK Chief Medical Officer highlighted the fact that research in children with ME was an urgent priority.

The scientific study of ME in adults is sparse given the extent of the problem, but in terms of children it is almost non-existent. MERGE and The Young ME Sufferers Trust believe that work in this area is crucial, as studies suggest that ME is the commonest cause of long-term sickness absence from school in previously fit children.

The Study

Title: An Investigation into Biochemical and Blood Flow Aspects of ME/CFS in Children

Researchers: The study will be under the direction of Dr Gwen Kennedy (Research Fellow) and Professor Jill J F Belch (Professor of Vascular Medicine) at the Vascular Diseases Research Unit, University Department of Medicine, Ninewells Hospital Medical School, Dundee DD1 9SY. In the past 15 years, this research group has published more than 250 peer-reviewed scientific papers relating to inflammation and vascular disease, and over the past 4 years has been investigating ME/CFS in adults. The study on children is an extension of this work on adults.

Background and Aim: Previous work by these researchers, using sophisticated vascular imaging techniques, has shown biochemical abnormalities in

the circulation of adult ME patients, suggesting that ME might result from a continuing challenge to the immune system.

The aim of the newly-funded study is to investigate a group of children with well-defined ME/CFS (in whom there is the possibility of long-lasting chronic ill-health) to see - for the first time - if similar biochemical abnormalities exist as those already observed in adults with ME. If they do, children with ME/CFS may have signs of a chronic inflammatory disorder associated with increased risk factors for cardiovascular disease, but encouragingly the findings might become the basis for future treatment interventions.

Unique

This study is unique in that it is the first to investigate biomedical markers in children with CFS/ME and fits in well with the UK Chief Medical Officer's call in 2002 for further research in this field.

Experiments

The study will recruit 25 children with well-defined ME/CFS along with 25 age- and gender-matched 'control' children. Each child will have a) A medical examination; b) Blood tests consisting of a standard full blood count, measurements of oxidative stress (eg oxLDL and plasma isoprostanes in the blood), cholesterol measurements (HDL, LDL & triglycerides); C-reactive protein (an indicator of inflammation will be measured by a high sensitivity ELISA); and apoptosis measurements. In addition, blood flow responses to acetylcholine will be measured using a scanning laser Doppler imager.

Timescale

Recruitment for the study will begin in the Spring of 2005, and results should be available about 18 months afterwards.

DR VANCE SPENCE

The Chairman of MERGE talks to Jane Colby

Jane: We both agree, don't we, that biological research into ME in children is vital?

Vance: Absolutely vital. And it's not being done.

Jane: So it's particularly important to do this study in children.

Vance: Yes, Jane, it is. And it's important for a number of reasons. Firstly, no other studies of a biological nature have been done on children with ME. This is a first. Now that's incredible, given that there are probably around 20,000 children with ME in the UK alone.

Secondly, we've already uncovered biochemical abnormalities in the circulation of adult ME patients.

Jane: How did you do that?

Vance: We used sophisticated laser imaging and laboratory techniques looking at the blood.

Jane: And what were the results?

Vance: The results suggested that ME might be maintained by a continuing challenge to the immune system.

Jane: In other words, a persistent infection of some kind, that keeps the immune system working all the time to try and eliminate it.

Vance: Exactly, the sort of thing that happens after an initial viral infection. And this immune disturbance may be responsible for the production of free radicals that we found in adult patients.



From a long-term perspective we thought it was vital to see

Dr Vance A Spence is Senior Research Fellow, Cardiovascular Research Institute, Department of Medicine, University of Dundee.

if these same biochemical abnormalities also existed in children with ME.

Jane: I understand that Professor Jill Belch and the team have a great deal of experience in vascular research? And also a lot of experience of working with children.

Vance: They certainly do. The department where the tests will be carried out has substantial experience working with diabetic children, so we are tapping into all this expertise.

Jane: One thing that concerns us is that the main medical journals seem to publish so little research into the physical nature of ME.

Vance: Journals make decisions to publish articles based on the quality of the science that is presented to them.

Jane: So do you think they pay enough attention to the physical causes of ME?

Vance: Probably not, but there really isn't much biological research going on at the moment, despite the extent of the problem.

I think the problem exists at a funding level – if money was available for biological researchers then the journals would have far more papers of relevance, it's as simple as that.

But that's only half the battle. The other is to identify good basic, biological and biomedical scientists with a track record in getting things done, people who are willing to take ME research programmes forward – month on month, year on year. Both aspects are a great challenge. And urgent ones.

Jane: What are the dangers for patients if not enough attention is given to the physical nature of the illness?

Vance: The main danger, Jane, is that we will never get to the bottom of this terrible condition.

Jane: And then, presumably, psychiatric treatments will go on being seen as all that can be offered, when it may be of little use, or even inappropriate for some people.

Vance: Well, the present research picture is heavily skewed towards psychiatry and psychology. The so-called 'best evidence' for treatment using cognitive behaviour therapy and graded exercise should really read, 'the evidence available after funding has been selectively acquired by biopsychosocial professionals'!

Jane: Quite!

Vance: So we've got to change that, otherwise the prevailing view of doctors – in the UK at least – will be that ME is basically a psychological condition. And very sick patients will continue to be sidelined. After all, it's a double torture: having the illness and having it unrecognised.

Jane: What potential do you feel our study has, in terms of diagnostic markers?

Vance: The problem with research is that you never quite know what you are going to find. If we did know then we wouldn't need the research! A diagnostic marker is something that is very special - it's the Holy Grail of scientific enquiry. While we hope for this, our expectations are more realistic. An indication of a treatment intervention is hoped for, however.

Jane: Is there anything else you'd like to add?

Vance: Yes, Jane, I would simply like to thank the Tymes Trust for their significant contribution towards this vital research project. To go back to your first question, it is in our opinion a vital project.

Jane: It has quite a long name of course?

Vance: It does. The title is 'An Investigation into Biochemical and Blood Flow Aspects of ME/CFS in Children'.

Jane: And when can we start?

Vance: We hope to get this underway in Spring – the Spring of 2005. The results should be available within 18 months.

Jane: And like all research, it is costly.

Vance: The cost is almost £42,000. That might sound a lot, but in research terms it is actually very small. Compare it with the almost £4 million recently allocated by the Medical Research Council for psychological management techniques which are designed to 'manage' the illness (whatever that means) not cure it.

Goodness, if we had that money for biomedical research, what could we not do!

The Young ME Sufferers Trust would like to thank the 2001 Odyssey and other donors for raising the funds to enable us to commission this study with MERGE.

Raising Funds for Research

Kaan, the amazing Akhal-teke stallion from Turkmenistan, was ridden by celebrities and volunteers the whole length of England and across the border into Scotland to raise funds for this research.



The 2001 Odyssey team arrive at Edinburgh Castle after riding up the Royal Mile to complete their marathon fund-raising trek from Lulworth Cove, Dorset.

Is Your Local Education Authority Listed here?

The Chief Medical Officer's Working Group on CFS/ME (Department of Health Report 2002) stated:

‘Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning.’

‘Some [...] may need home tuition and/or distance learning on a longer-term basis. This may require information and communications technology, which can also help improve social contact.’

Writing about the April launch of our partnership with Nisai Education in the House of Lords, Earl Howe said:

‘Our shared aim must be to roll out the virtual classroom, with all its benefits, to many more children with ME over the months ahead. With the energy and dedication of The Young ME Sufferers Trust and their partners at Nisai, I am convinced that this aim will be achieved.’

Progress has indeed been made. Here is the list of present partners and clients. If your LEA isn't here, why not ask them to get involved.

| | | |
|---------------------------|------------------------------------------------------------|-----------------------------------|
| Barnsley LEA | Kensington & Chelsea | St Helens LEA |
| East Riding of Yorkshire | London Borough of Hillingdon | Manchester LEA |
| Calderdale LEA | London Borough of Hounslow | Surrey |
| Hartlepool LEA | Manchester City | Somerset LEA |
| Cambridge LEA | Cornwall LEA | The Birmingham Grid for Learning |
| Derby LEA | Norfolk LEA | Trinity College – Dublin |
| Cornwall LEA | Nottinghamshire LEA | The Scottish Agricultural College |
| Derbyshire LEA | Plymouth LEA | University of Reading |
| Cumbria LEA | Solihull LEA | Thurrock LEA |
| Nottingham City LEA | Powys LEA | Trafford LEA |
| East Ayrshire Council | Southampton | University of York |
| North Ayrshire Council | Raynes Park High School – London | Carlos III University – Madrid |
| Gateshead | Royal Manchester Children's Hospital | Wigan LEA |
| Bolton LEA | Wirral Hospital | Warrington |
| Gwynedd LEA | South Eastern Education & Library Board – Northern Ireland | Wiltshire LEA |
| Hertfordshire LEA | Ireland | North Somerset LEA |
| Hampshire LEA | Portsmouth | Worcester |
| Isle of Wight LEA | Staffordshire LEA | Liverpool City LEA |
| Knowsley LEA | Warwickshire LEA | Harrow College |
| Bournemouth LEA | | |
| London Borough of Bromley | | |
| London Borough of | | |

If you weren't with us at the start of this venture, the virtual classroom is an internet system that can be used by anyone with a standard computer. Any internet connection will do, *even a normal telephone line!* It hosts live, tutor-led classes, especially for pupils unable to access school. LEAs usually pay the fees.

To find out how you can become involved, contact Andy McGarry at Nisai Education on 020 8424 8475. Do also let Andy know your own experiences with the virtual classroom as feedback is vital in order to make sure that everyone gets what they need.

You Tell Us

I smile
Because things are different now
I cry
Because they are just the same
I smile
Because my dreams are coming true
I cry
Because they're changing
I smile
Because I've learnt to live
I cry
Because I've forgotten how I did before
I smile
Because the sun always shines
I cry
Because I'm yet to see it
I smile
Because I've tasted life
I cry
Because life won't let me take a bite
And yet I smile
A lot of the time....



My daughter Suzanna has had ME since age 11 and has rarely been to school since then. Through home tuition (when well enough) her GCSE grades were: A* English Language, A German, B English Literature, B Maths, BB dual award Science. She passed against all the odds. The school were never supportive, forgot to enter her for maths and sent the wrong exam paper home twice – not to mention not applying for special exam arrangements in time, although I kept reminding them. She is doing AS levels with a local college. I am so proud of her for keeping going.

Jacqueline Simpson

If we didn't feature you this time, we'll try and do so next time. Come on you guys – what have you been doing?

Eleanor Ward

It has taken 10 long years for my daughter Catherine to be well enough to begin to have a normal life. She met Matthew in 2000 when she began to go out socially. She got married a year ago and has started a sandwich business after working part-time for a while. After 3 weeks, she was awarded a gold certificate for hygiene. I still worry about her, especially with the amount she does, but she is a bit old to be lectured now! Catherine's recovery was so slow, we could hardly tell it was happening. The only thing that really helped was listening to her body and resting when necessary.



I was so excited about taking part in the Sport Relief Mile. I wore a hula girl outfit and my one red sock. Prince William was in front. I decided to walk and I kept stopping so I felt OK. On the route I saw a Scooby-Do, fairies and schoolgirls with their feet tied together! At the end I met Connie from Blue Peter. They gave me my other sock and a goody bag – then I went home to bathe my feet.

Shannen Dabson

Carole Lewis

BAD TIMES

by Emma Gray

My life revolves around the word 'ME'.
Why can't it just be 'me'?

Some days I feel I want to cry and
Some days I just ask - why?
Why do I have to cope with this,
While other people just get missed?

I have everybody else's share.
Surely - this can't be fair?

Lying in my room all day
While other kids go out and play.
Pain and sickness I still feel
Some days it just feels surreal.

I lie in a darkened room
Cause my head is pounding like a drill

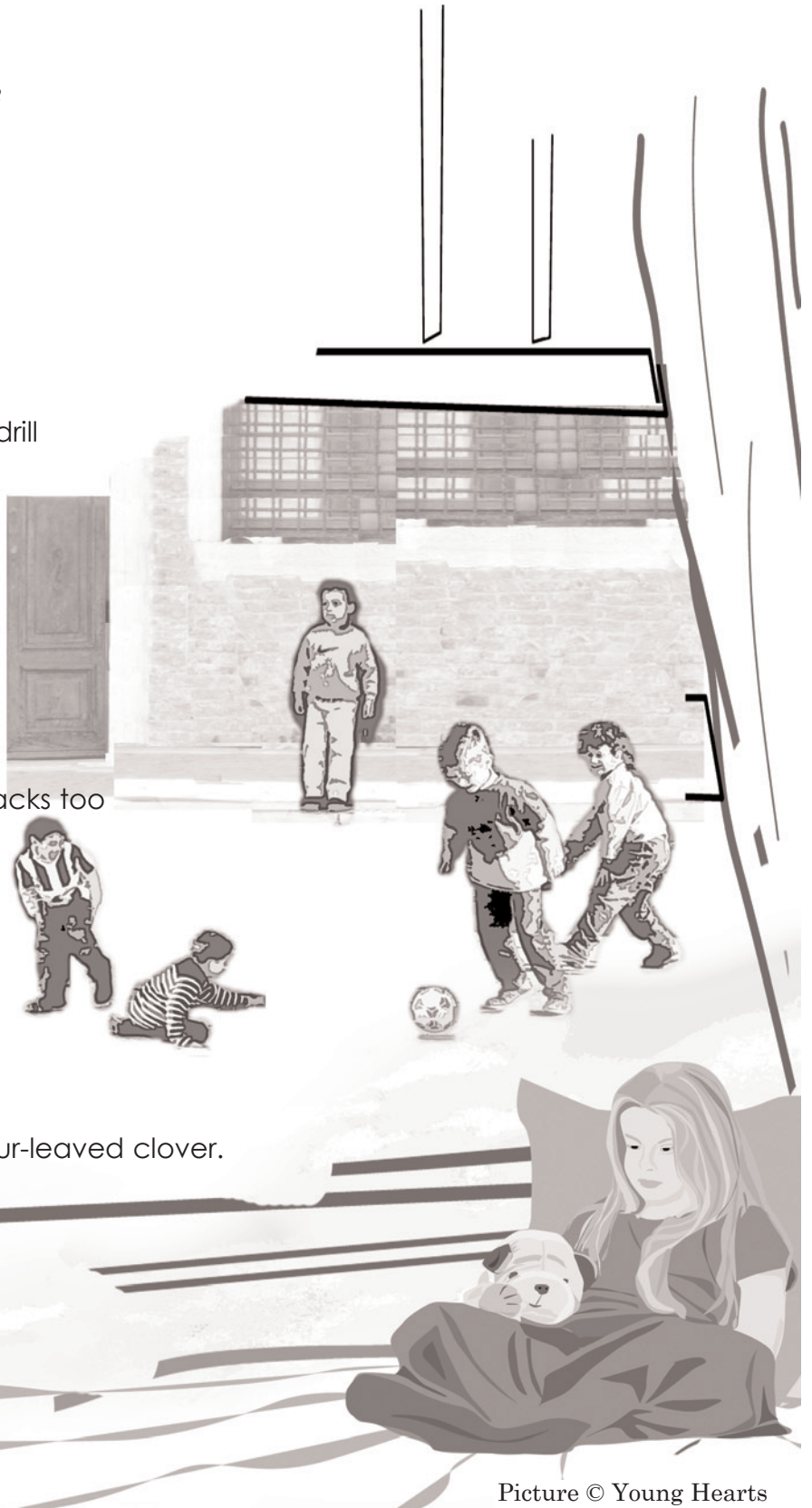
Crying with the pain and anger
All the while it just gets stronger.
Why do people have to shout?
Why can't I just get out?

Food is a horrible word
To me it just sounds obscured.
Lie in bed all day sleeping
Oh, I wish I could be dreaming.

Night sweats, headaches, pain attacks too
Are just some, to name a few.

The nightmares can be the worst.
Surely - it must be cursed.
Hazy head, fuzz and fog -
Find someone to lift this smog!
Lying in my darkened room
With hat, scarf and sunglasses too
Waiting for it all to be over.

I think, for that, I'll have to find a four-leaved clover.



Picture © Young Hearts

SEB'S MANOR



by Sebastian the website spider
(find him at
www.youngactiononline.com)



Sebastian says:

I've got it! An exclusive and lovely poem NOT featured in *Young Hearts*. As a poet of renown myself, I wanted a new poem for my new pages in *Vision!*

When 'Pillow of Secrets' arrived (the book was already going to print) I *pounced*. Spiders do that... I expect you've noticed.

AND I've been sent hugs by the last of our Beefeater Bears to go out into the world. He's finally found a loving home with Hannah, one of our new members. He was feeling really down because *no-one* had sent for him. You can see Hannah's first card here:

Hannah's second card says: "Pretzel sends Seb spidery hugs!" So I have to show you that one too, don't I?



★Thanks★

★Thanks★

Dear Keith & Staff / Trustees at
Tymes,
Thankyou Ever so much for the
lovely "Beefeater" bear, he is very
Cute.
I really appreciate you sending
him to me (He's very welcome 😊).
I have named him Pretzel.
Thankyou again.
Love from, Hannah XX

Beautifully
illustrated by
Hannah



PILLOW OF SECRETS

Sorrow, anger and sweet bliss,
Many times I have cried into soft
nothingness.

My pillow may be battered, but I do not care,
For my pillow holds secrets special and rare.
Love lost and love gained,
Many boys' names remain.
Sorrow, anger and sweet bliss,
My secrets are sealed with a hug and a kiss.

Bethany Taylor



Picture © *Young Hearts*



A special message from international motorsport's Chris Dyson.

'In motor racing it's always important to focus on the bright spots, and keep your head up, because it's a very difficult and competitive business. I would urge all of you to always concentrate on the positives of every day, and to look ahead to a brighter future.'



Dyson Racing : American Le Mans Series.

Chris's co-drivers are featured at www.tymestrust.org with their own special messages for you.

Email:

I am just emailing to say thank you ever so much for sending me a prize for my entry in the Shirley Conran letter writing competition. It really cheered me up! I wrote in practice for my English Language GCSE paper and I got an A* so I am doubly grateful.

With the Amazon token I have ordered a book about the comedy TV series FRIENDS. I have wanted it for ages so I am really pleased that I have been able to buy it as I really wanted some fun, light reading!

Thanks again.
Bethany Reid



Message from Julie Neyt

"Hello! Fudge Beanie Bear and Max Beefeater Bear have been busy helping Cheryll settle in at college but send thanks and good wishes to Seb and hope he's not too upset about them taking over his pages in the Summer?"

*Not at all.
I am Most Magnanimous.
Seb*



We'd all like to thank our resident Santas, June and Roger Scott, for their kind gift of greetings cards for our members.



A City bank's Employee Christmas Club of 20 people, run by Andrea Foster and Liz Hughes, has donated their interest to the Trust, which was matched by their employer. Many thanks to you all for your generosity.

True Funnies

(send me yours)

Overheard in the office: 'Mark's given me a coffee mug that says: "DON'T LIE – The Computer Didn't Just Do It!!!" How well he knows me!'



Quotes-I-Like

(send me quotes to choose from and I'll publish them with your name)

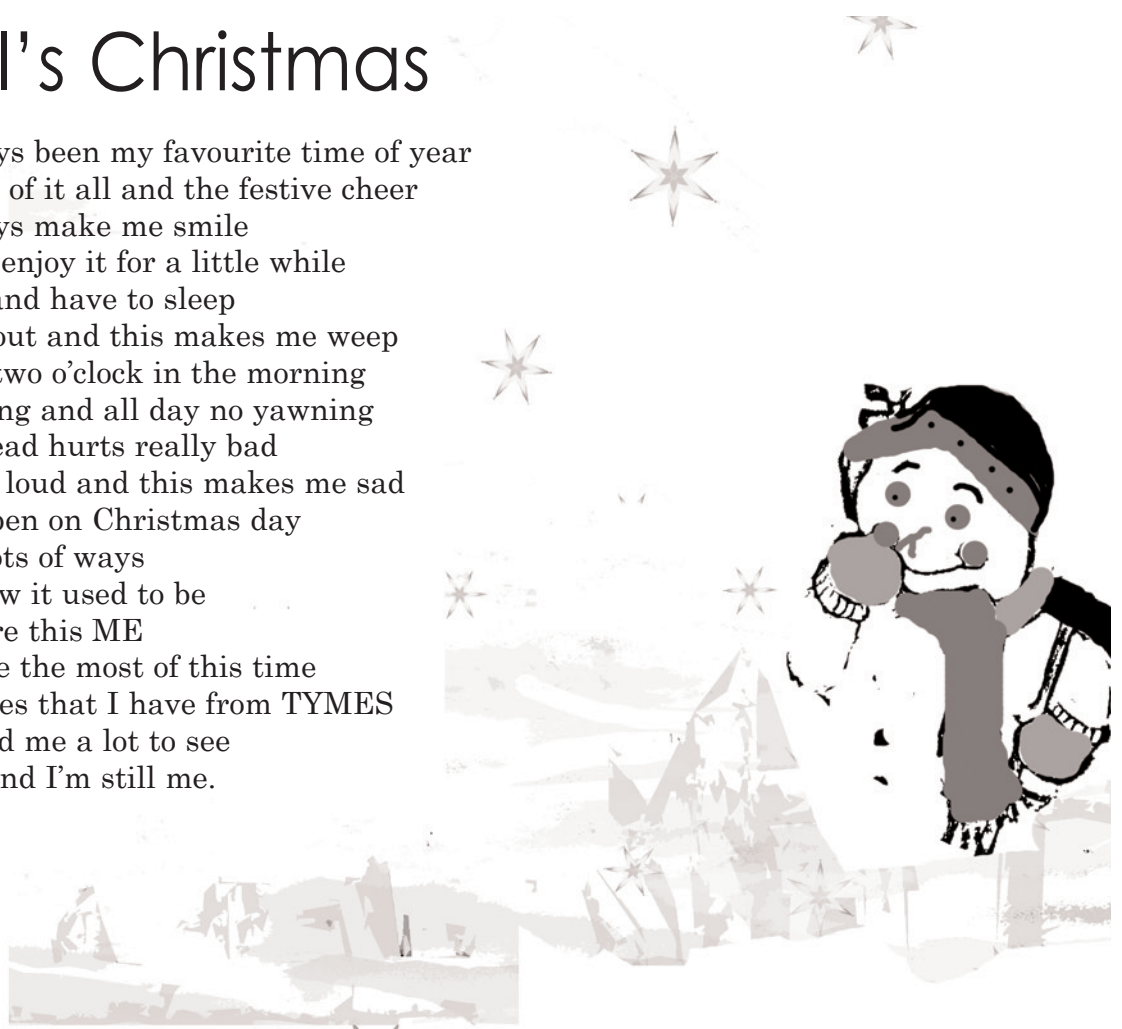
'It's the friends you can count on that matter, not the number of friends you can count.'

Anon

Rachael's Christmas

Christmas has always been my favourite time of year
I just love the magic of it all and the festive cheer
Christmas can always make me smile
But I'm only able to enjoy it for a little while
Because I get tired and have to sleep
I know I'm missing out and this makes me weep
No more waking at two o'clock in the morning
To look in my stocking and all day no yawning
On some days my head hurts really bad
And sounds seem so loud and this makes me sad
And this might happen on Christmas day
To spoil my fun in lots of ways
I wish it could be how it used to be
Before I got ill, before this ME
But I'll try and make the most of this time
And all the magazines that I have from TYMES
The Trust has helped me a lot to see
That I'm not alone and I'm still me.

Rachael Marshall



Christmas Eve Night

Sparkling snowflakes flutter softly down
And settle upon the cold still ground
While inside all is wrapped up warm and tight
In the quiet stillness of Christmas Eve night
Stockings hang full on every bedroom door
Children sleep softly dreaming of presents galore
Under the twinkling lights of the Christmas tree
Wait the wrapped presents for all to see
On the table stands an empty glass of port
And crumbs from a mince pie for Santa of course
All through the silent house nothing stirs
This peaceful magic time that only occurs
As Christmas Eve night sleepily waits for day to come
For the festivities to start and the laughter and fun
And the snow continues to settle and fall
A perfect white Christmas Eve night for all

Rachael Marshall



Picture © Young Hearts

Soul in the City

I'm 23 and I've had ME for 4 years. Just before I got ill I spent a year as a children's worker in a church near Liverpool. I was always busy and I had a lot of fun. Since then I haven't been able to do anything like that because I've been too ill, but this summer I was well enough to go to Soul in the City. Twenty-six of us stayed in a church hall and worked together as a team.

I was on the youth project and spent afternoons at a youth club, joining in activities and having fun with the kids, who were mainly 11-13. I spent most of the week braiding hair, which took a long time, but was a great opportunity to talk to the girls.

In the evenings we went to Club Constellation. We had older teens then, and various Christian bands played. Some of us went to parks and round the streets to talk to the young people who were hanging around, while the rest of us stayed in the club and talked to the kids there.

On Wednesday night there was a foam party in Moredon park organised by Soul in the City with bands playing and lots of foam! Some of the kids from the club went, and managed to avoid the foam, which is more than I did!!!

I will never forget that week. It was an amazing time, although I found it really hard. I didn't manage everything because I had to rest, but I missed a different thing each day so I didn't feel I missed too much.

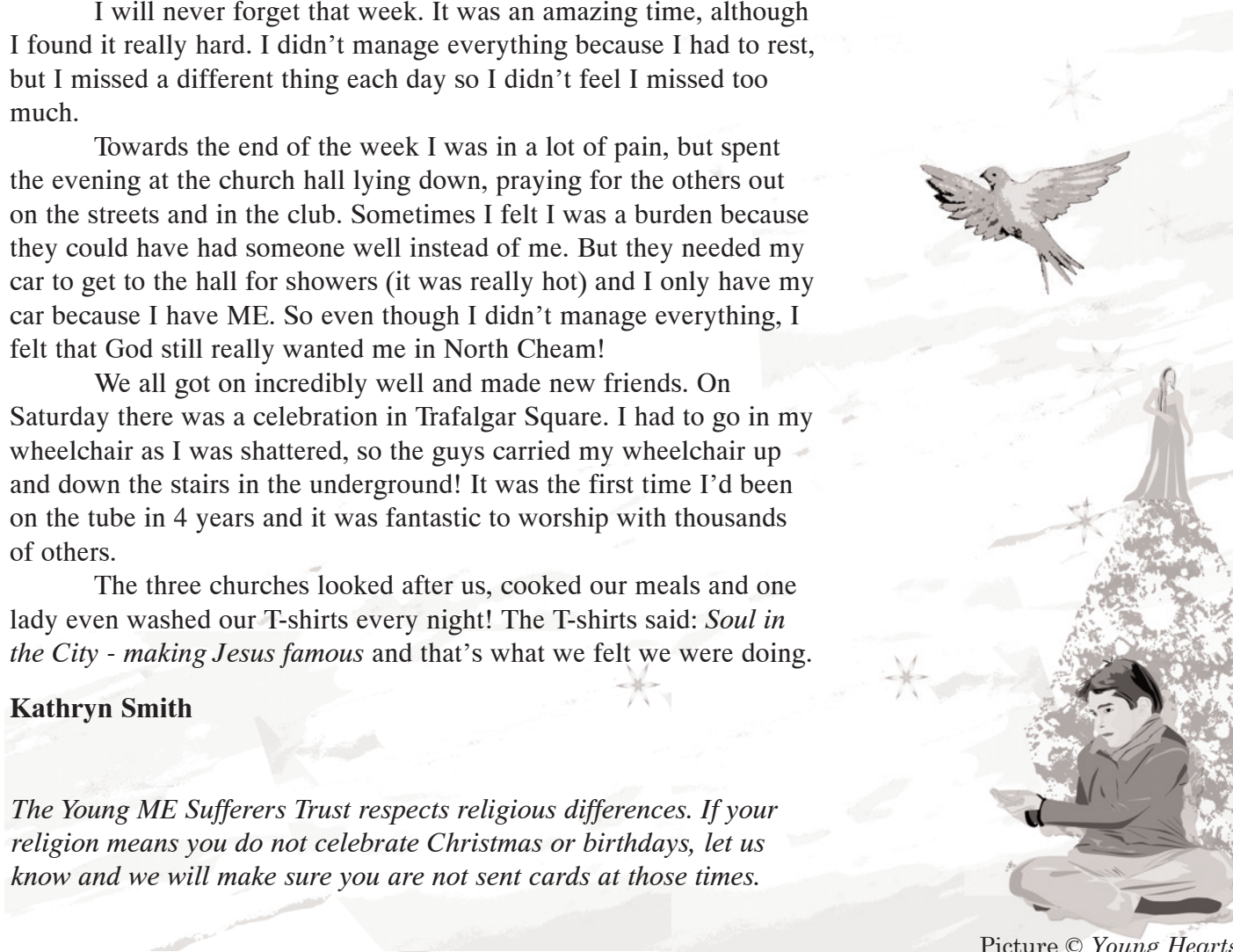
Towards the end of the week I was in a lot of pain, but spent the evening at the church hall lying down, praying for the others out on the streets and in the club. Sometimes I felt I was a burden because they could have had someone well instead of me. But they needed my car to get to the hall for showers (it was really hot) and I only have my car because I have ME. So even though I didn't manage everything, I felt that God still really wanted me in North Cheam!

We all got on incredibly well and made new friends. On Saturday there was a celebration in Trafalgar Square. I had to go in my wheelchair as I was shattered, so the guys carried my wheelchair up and down the stairs in the underground! It was the first time I'd been on the tube in 4 years and it was fantastic to worship with thousands of others.

The three churches looked after us, cooked our meals and one lady even washed our T-shirts every night! The T-shirts said: *Soul in the City - making Jesus famous* and that's what we felt we were doing.

Kathryn Smith

The Young ME Sufferers Trust respects religious differences. If your religion means you do not celebrate Christmas or birthdays, let us know and we will make sure you are not sent cards at those times.



Picture © Young Hearts



Young Hearts

Inspirational Poetry

by children and young people with ME

Foreword by Terry Waite CBE

Former Envoy to the Archbishop of Canterbury

Fourteen year old Jade Louise Scarrott lived with ME, expressing her fears and hopes in moving poems. Her dream of helping other children and young people with ME to do the same seemed to be over when her life was lost in a random accident on our roads. But this book, published in her memory, has turned her dream into reality.

'Suffering comes to all of us but not in equal degree. Some certainly suffer more than others and through no fault of their own. All we can say with certainty is that so very often something creative can emerge from the deepest grief.' **Terry Waite CBE**

'Some of these poems moved us to tears. Others made us smile. Above all, we found them inspirational.' **Jane Colby FRSA**

'Jade's story is tragic, but I am very glad that her wonderful idea for this anthology is being carried out.' **Katie from South Africa**

'I think what Jade wanted to do was a great thing - many people don't understand what it feels like to have ME when you're young.'
Rachael Marshall

'I love what you're doing with the Young Hearts book, I think it's a beautiful idea, it really touched me, let's hope it does the same for many more and raise up the awareness as was intended.' **Emma Patrick**

'I would love to give a little happiness to those who add to the book. I believe when you do something that you're a part of, with others who are just like you, it gives a sense of life - even if some of the kids with ME can't experience "life" first hand.' **Jade Louise Scarrott**

To see *Young Hearts* in glorious blue, go to www.tymestrust.org
To order, send your cheque for £7.95 to Young Hearts, PO Box 4347, Stock, Ingestone, CM4 9TE or telephone 01245 401080 for our credit card facility.



Taking our work home with us!



Kerry-Ann Edge and Jane Colby abandon the computer to assemble the final jigsaw



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 ICD 10 G 93.3