



The Young ME Sufferers Trust

www.tymestrust.org

TYMES MAGAZINE

Issue 48 Summer 2004 £1-95

THE VIRTUAL
CLASSROOM
Earl Howe

EXPLORING
Anti-Viral Drugs

HOUSE OF LORDS
LAUNCH
Lord Clement-Jones

DO FAMILIES WANT
PSYCHIATRISTS?
We Investigate



SHIRLEY CONRAN HONOURED WITH OBE

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TYMES TRUST

Registered Charity Number 1080985

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

Postal Address: PO Box 4347, Stock,
Ingatestone, CM4 9TE

Website: www.tymestrust.org

Partner: www.youngactiononline.com

Advice Line and enquiries: 01245 40 10 80

Advice Line Hours: Weekdays 11am-1pm &
5pm-7pm

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

WHAT YOU THINK

Thank you again for everything you are doing at the Tymes Trust which is such a positive lifeline for Elizabeth and ourselves.

Jane Colley

Just to let you know that I sent Sandi Toksvig who is a presenter on LBC Radio an email asking her to read out the Tymes Trust web address; told them what a life saver your organisation had been for us as a family. I was so glad she read it out.

Karen Stone

Thank you so much for everything you are doing to support us, words seem very inadequate for the help that people are giving but all we have to offer and we are more grateful than you'll ever know.

Debbie Storey

On behalf of the National ME/FM Action Network of Canada, I would like to congratulate you for all the wonderful work you have done on behalf of children and youth with ME. Establishing Tymes Trustcards for young ME sufferers is but one of your many impressive accomplishments.

My son is making us a new website and I am looking after the content. As I had taught school for 18 years before becoming ill with ME and FM, I am eager to expand the youth section. We have a link to your partner site Young Action Online. Would you kindly give permission to also link to www.tymestrust.org ? These websites are most informative and there is nothing comparable to them in Canada.

I would also like to post your interview with Terry Waite from the *Tymes Magazine* Issue 44, Summer 2003 on our site. The gems of wisdom contained in this interview should uplift and benefit all people with chronic illnesses.

The Canadian ME and Fibromyalgia Syndrome Consensus Documents can be found on our website www.mefmaction.net

Marjorie van de Sande

Director of Education

[Thank you, Marjorie. Permission granted. Ed]



Dear Reader

Our summer theme *Succeeding with ME* can mean many things. Learning to live with and manage your illness is a difficult challenge at best. In severe cases it means finding inner strength to endure through the worst. We are especially mindful of you and your families and we send you all our love.



Shirley Conran OBE

We are delighted that best-selling author Shirley Conran, who reads, recommends and contributes to *Tymes Magazine*, has been honoured with an OBE for services to equal opportunities, which, as she explains, includes everyone with ME. Shirley is

President of the Work-Life Balance Trust and has suffered with ME for over thirty years. Her first public interview about this appeared in *Tymes Magazine* Issue 41.

Our magazine designer, Kerry-Ann, has just completed a degree in graphic design. Kerry-Ann was born and brought up in South Africa, where she was one of the first teenagers diagnosed with ME. We have changed our summer schedule to help her complete her dissertation and mount a London exhibition of her work. Success means different things to different people.

Can we help *you* to succeed? Our new education partnership, launched in the House of Lords, may be the answer. As Dr Alan Franklin once said: 'If the child doesn't fit the system, then the system is wrong.'

Jane Colby
Executive Director

IN THE SPOTLIGHT: THE TYMES TRUST VIEW

The BMA's *Complete Family Health Encyclopedia* states: 'In Munchausen's Syndrome by Proxy (MSBP) parents cause factitious disorders in their children.'

Parents are reporting to us that they have found MSBP mentioned in their own or their child's records. Suspicions that parents may have harmed their children can spark off child protection procedures, particularly where disputes arise over treatment or school attendance.

Allegations of MSBP fail in law when a medical condition explains the symptoms, but diagnosis may take weeks, months, even years. When ME/CFS is finally diagnosed, medically unqualified people may still doubt it.

Case 1: A mother could not find a job; her medical records showed she was suspected of MSBP.

Case 2: A child's school records showed that teachers had queried a diagnosis of ME/CFS and were trying to impose an

unsuitable regime. Anyone not medically qualified cannot make this judgement.

Case 3: A mother found that her daughter was thought to be suffering from Pervasive Refusal Syndrome (PRS), a psychiatric term meaning total withdrawal, possibly due to child abuse. Refusing to eat, wash or undertake personal care are symptoms. But severe ME/CFS can make a child too weak to eat or wash. Querying diagnosis or refusing treatment is listed as *characteristic* of a parent whose child suffers from PRS. Query the diagnosis and you confirm it.

Records can have corrections added. We advise families to check their own and/or their child's medical and school records if they have concerns.

For an article on Pervasive Refusal Syndrome send £1.50 to The Young ME Sufferers Trust.

The Click-On Classroom

The Times 21 April 2004

In a full-page feature on the Virtual Classroom, Jerome Burne reminded readers that the Chief Medical Officer's Working Group on CFS/ME recommended that 'e-learning provision should be made for sick children to study properly at home.' He continued: 'A partnership between the Young ME Sufferers Trust (the Tymes Trust) and Nisai, a web-learning company, is being launched at the House of Lords next week.'

Describing how difficult things had been for our young member Ben Bryant, Jerome wrote: 'All that changed for Ben when he became part of a project that promises to transform the way children



who cannot go to school are taught. Already, several hundred have been supplied with the computer equipment necessary to use a virtual classroom. Impetus for the scheme came from Jane Colby, a former headmistress and now Director of the Tymes Trust. "ME is the biggest cause of long-term sickness absence from school," she says, "and conventional education is a key cause of relapse."

Jerome explained how Warwickshire Local Education Authority has been developing the scheme, which is now available nationwide. "The latest GCSE results are the first proof of how well the new system is working. "They were the best we have ever had with these children," [David] Teece says.' A success rate of 96% A-C pass rate as against the usual 51% was quoted.

News Review

Controversial Study by Great Ormond Street Hospital Physicians

Source: Medscape

Date: June 28, 2004

Author: Laurie Barclay, MD

URL: <http://www.medscape.com/viewarticle/481996>

Dr Barclay writes that 'Outpatient rehabilitation improves "Wellness" scores and school attendance for adolescents with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), according to a study published in the July issue of the *Archives of Disease in Childhood*.'

He quotes the researchers from Great Ormond Street Hospital: "A number of reports suggest that the most appropriate treatment for CFS/ME in children and adolescents is multidisciplinary rehabilitative treatment, with an emphasis on increasing activities alongside symptom management and addressing psychological issues through systemic (family) approaches. This approach is based on [...] a recognition that the syndrome may be [...] a chronic state of low physical and emotional functioning where biological causal factors may no longer be operative, but illness is maintained by physical deconditioning, sleep disturbance, and psychosocial factors."

We have looked at this study in detail because families may have the results quoted as a reason to allow their child to undergo a similar regime.

It appears that the researchers used a non-randomised method of selection – all those who were referred and met the criteria were given the option of being included in the programme. So they were self-selected and we are therefore not surprised that 63% of severe cases who chose not to undergo the programme but only to receive supportive care were still ill at the end of the two years. Parents of severely ill children, based on their own experience, do not generally wish them to undergo increases in activity.

If they had chosen to participate in the programme, would their children have improved, stayed the same or deteriorated, as so many have under similar programmes? We shall never know, but we would advise caution with any such scheme or programme.

The children were diagnosed using the CDC diagnostic criteria. This may have pulled in children

who do *not* have the potentially severe and chronic neurological condition known as ME.

We note that ethical approval was not obtained as the researchers compared 'different forms of current management'. They also used subjective data, not objective tests, to judge the success of their programme. They asked how the children felt, for example (many children like to please and try hard to say what their elders would like to hear) and they also used school attendance as a marker of 'functional status' and 'ability to participate in normal life'.

Many children with ME try to attend school simply as a result of being made to feel that this is where they belong, even when unwell. No mention is made in the study of their educational rights or what their level of educational achievement was as a result of going into school.

To summarise: it is possible that those families who did not fancy the treatment programme were those who realised already that their child's illness was less amenable to such treatment. Does this mean that they were more likely to have the genuine, neurological ME as opposed to other sorts of fatigue illnesses, trapped in the same study under the CDC definition? The use of the Canadian criteria would arguably have told us more.

No mention is made in the study of their educational rights or what their level of educational achievement was as a result of going into school.

Sadly, the researchers suggest that it was those who were more motivated to change who entered the programme. Yet they admit that those who took part may have been given more intensive support generally.

Although they knew who was on their programme and who wasn't, the researchers argue that the outcomes could not have been affected because the reports were 'generated' by the subjects themselves. But since these subjects knew what was expected of them, were they influenced to put down what the therapists wanted? We call this the Dr Chris Rolles effect, which he so eloquently described to us. *For more information, please contact our Advice Line.*

Why Won't They Believe Me?

The Independent Review 10 May 2004

The Young ME Sufferers Trust was quoted in a full page feature by Jerome Burne severely criticising new trials of CBT, Graded Exercise and a hybrid form of Pacing. 'Funded by the Medical Research Council at a cost of more than £2.5m, the trials are just getting underway. "Whatever their findings," says Dr Vance Spence, Senior Research Fellow at Dundee University and a leading scientist in the field, "they won't tell us anything useful about the best way to treat CFS/ME because they are not properly selecting patients with the disease. There is widespread concern about this."

Jane Colby was quoted: "If the Canadian Definition were to be taken into widespread use, it would be much harder for people with chronic fatigue to be categorised along with those who have true CFS/ME." The MRC says it is seeking new research proposals and there is no reason why projects using the Canadian Definition should not be accepted in future.' The Trust will be pressing for this.

Breaking News

Every student knows what it is like waiting for results. Finally, for our graphic designer Kerry-Ann Edge, the suspense was over! She was given a 2:1 grading for her BA(Hons) Graphic Design degree.

'My third year was divided into two main sections - the dissertation and the final major. For my dissertation I researched the effect of animation on young children. The final major included an exhibition, which was held in London and 800 people attended.'

Part of the exhibition time line showing the historical changes influencing a woman's image.

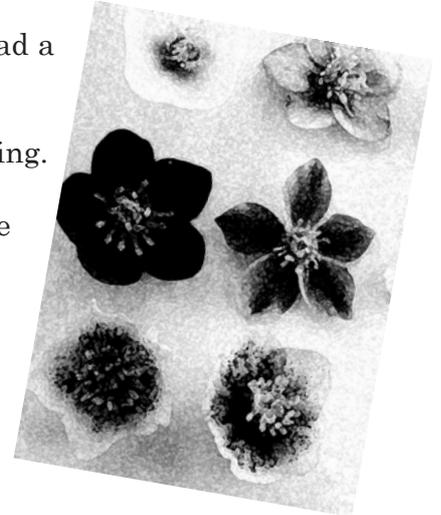


WHEN IS YOUR BIRTHDAY?

Have you accepted your birthday invitation to tell us how you are?

Thank you so much for my birthday card you sent for my 18th. I had a lovely day and in the evening went for an Italian meal with my boyfriend and best friend. I had lots of prezzies. My health is improving but I had to drop out of college as I found it too exhausting. I have been doing a home study course. After this, I'm not sure; maybe I will do an Open University course but my health will come first. Keep up the good work at Tymes Trust – without your advice and help, this illness would be harder to cope with. My mum and I have found your magazine most helpful.

Best wishes
Sarah Colson



We hope your June GCSEs went well, Sarah.



Sazza and her friends enjoying themselves



Thank you ever so much for another beautiful birthday card and invitation. It is ever so special the effort you make in ensuring we all get one and how you endlessly sign them. I managed to have the best time yet, surrounded by my family and feeling the presence of my priceless friends in spirit. I've learned that every setback is just an opportunity in disguise (actually I nicked that saying but hey, ho!) I can honestly say I wake up daily with a propeller of hope inside my head, a gallon of belief swelling my heart. My sticks remain in the house, my wheelchair stagnates silently. I look forward to the day I'm free enough to return them but until then, my therapists have told me, it's best to have them handy. I'm semi-recovering – it's all a balancing act.

With love and thanks for all the support and encouragement to help get me to this point. I won't forget it.
Sazza Holmes

PS I passed my OCN Level 3 Costume Design with a distinction!

I am 11 years old and have been off school for 7 months now. I really wanted a bowling party for my birthday, but as I was too ill, I was not able to have one. My mom and dad came up with the fantastic idea of going to a bird of prey centre near where I live. I was able to fly and handle the owls, buzzards and kestrels and I got to hold Lenny, the spiny lizard. The photo is of me with Kyla the buzzard at Gentleshaw Wildlife Sanctuary and in the end it turned out to be the best birthday ever!



Rebecca Stokes with Kyla the buzzard

Love from
 xxxxxxxxxxxx
 x **Rebecca** x
 xxxxxxxxxxxx



Water colour painting of Elsie

Jenny Smith, Director of Gentleshaw Wildlife, says: 'I remember the young lady who came to see us, a very nice young lady and most cheerful.' You can find Gentleshaw Wildlife Sanctuary at: www.gentleshawwildlife.co.uk

News from Gentleshaw in Eccleshall, Staffordshire

June 2004 : We have some new arrivals at the centre - come along and see our 'babies'. Yerevan is a European Eagle owl. We also have been lucky to have some Snowy Owl chicks that hatched on the fourth of June and our garden pond is now home to a couple of Terrapins named 'Jaffa' and 'Cake'. Hopefully, there will also be a baby Great Grey Owl called 'Apache' joining us.



Photo by: Colin Kai Heaps

Photo by: Colin Kai Heaps



Owl photos courtesy of the Gentleshaw website. Do go and pay them a virtual visit - it's one of the easiest sites to use that we have come across.

'To everyone, a big hello, hoot, growl and sniff from all of the furry, feathered, scaly and human residents of Gentleshaw Wildlife Centre'
Yerevan



If for religious or other reasons you don't celebrate birthdays, let us know so that we can make other arrangements for you.

How about our lads? Write and tell us what you do on your birthday, guys - and more from the girls too please! You can email via the form at www.tymestrust.org or send a postcard.

Tymes Trust Team



My love and best wishes to you all

NAME: Jo-Anna Roberts

POSITION: Advice Line Team Member and Co-ordinator

BACKGROUND: I'm 20 and live in Llandudno, but I'm originally from Buckinghamshire. I've probably had ME since I was 9 and was diagnosed with PVFS in 1997. My incredibly supportive parents battled with my school to get me home tuition through 2 GCSEs and 1 A-level.

I have an education thanks to the advice of Tymes Trust. I moved to North Wales last summer after marrying Jon - the man of my dreams! Jon is 27 and loves music. He also has ME and has been ill since he was 15. I am now an Open University student and I'm thoroughly enjoying the experience.

HOBBIES AND INTERESTS: I love learning, reading, keeping in touch with friends, listening to music, poetry, history, psychology, dreaming of travel and exploring my Christian faith.

FAVOURITES: Book - 'Birdsong' by Sebastian Faulks; Film - 'It's a Wonderful Life'; Music - rock, jazz, classical and Christian; Food - anything 100% organic!

PERSONAL MESSAGE: I feel I have learnt to adapt to life with ME and have learnt to appreciate the simple things (spring flowers, raindrops on my window). I know the value of true friendship, and I've found the love of my life. I now know to be realistic (Sensible

is my middle name!) but I'll never lose sight of my dreams - they keep me sane.

I'm so happy to be part of the TYMES team. Using my experiences to help others is so rewarding. I hope to encourage others with ME to believe that they too can move forward with their lives and go in the direction they want. You needn't be defined by your illness.

Could you join us as part of the Tymes Trust Team?

Jo-Anna says: 'My father Barrie is on the Advice Line Team and I found myself getting very interested. It is the first time I have done anything like this, so it's exciting. There is so much knowledge in the pack from Tymes Trust that I feel confident I can have the right information to hand, or will know where to obtain it.'

Why not consider joining Jo-Anna on the Team? Fund-raisers would also be welcome.

Contact the Trust on 01245 401080 to discuss it

Angharad Davies from our Advice Line Team, is leaving us to begin full-time law training. We wish her every success.

Angharad writes: 'Thank you for being so kind, patient and welcoming me to the Team. I have thoroughly enjoyed my time with you and think that you provide an amazing service to those affected by ME.'

Insight: Top Tips

How to make a difference

Making a difference can take many forms. Some people share their stories with the press, others give information to schools, colleges and surgeries, some work with their local ME group, or fund-raise. Countless carers also make a personal difference to the lives of family and friends.

On a sunny day in May, Jane Colby addressed HERMES (Herts East Region ME Support) on how The Young ME Sufferers Trust works to make a difference and gave tips on how you can too.



John Hayes, Chair of HERMES, with Jane Colby.

Photo by Sarah Harris

Making a Difference

Making a difference isn't rocket science
Do what you can, when you can
Take the long-term view
Cultivate staying power
Keep your focus
Be pro-active, not just reactive
Celebrate your victories
Support one another
Find the special skill you have
Then use it

© Jane Colby

Parliamentary News

In view of the ongoing public debate over the full name and classification of ME, our patron Lord Clement-Jones asked Her Majesty's Government whether they subscribe to the World Health Organisation's designation of ME as a neurological illness and whether they also subscribe to the title Myalgic Encephalomyelitis.

Confirming that the Government does subscribe to the WHO neurological classification, Lord Warner replied:

'Chronic Fatigue Syndrome/Myalgic Encephalomyelitis is an internationally recognised term for this condition and is used and understood by both clinicians and patients. The US Department of Health and Human Sciences Centres for Disease Control and Prevention adopted the name Chronic Fatigue Syndrome in 1988.

'There is much medical literature tied to the current name, and a change of name should wait at least until an accepted biological marker is found.

'Until a new name for this illness is agreed internationally we will have to continue to use Chronic Fatigue Syndrome/Myalgic Encephalomyelitis to describe it.'

Partner Group Invitation: why not meet up in Wales?

Barbara Turnbull of Clwyd ME Support Group writes to invite you to a get-together:

Thank you for the spring issue of *Tymes Magazine*. As ever it is great, and I very much enjoy it. Please may we reprint *A Mother's Eye View*, *A Good cup of Tea* and the cartoon *I love being outside in the Sun* by Laura Shave? [Yes-Ed]

I am looking to launch some young people's pages in our Newsletter, and hope to

interest them in getting together in some way. I would love to hear from any young people who would like to meet up or to contribute to our new young people's pages.

If you would like to contact Barbara, send us an email using the contact form at www.tymestrust.org or telephone 01245 401080. Otherwise send us a postcard with your details. We will pass on all your messages.

The Sky's the Limit

'Once again, I would like to thank The Young ME Sufferers Trust for their commitment to the education of children and young people with ME.' *Baroness Ashton of Upholland, Parliamentary Under-Secretary of State*

Following our House of Lords launch of the Tymes Trust/Nisai Education partnership hosted by Lord Clement-Jones, we presented our new document *Succeeding with ME* to Prime Minister Tony Blair's office on ME Awareness Day.

Mr Blair asked the Department for Education and Skills to examine this document. We have now received a most helpful reply from Baroness Ashton, who met with Jane Colby and Keith Harley in 2003 to discuss the problems faced by children with ME.

She writes: 'I agree that ICT has considerable potential to enhance the education of children who are unable to attend school because of medical needs. The Department's joint statutory guidance with the Department of Health *Access to Education for Children and Young People with Medical Needs* actively encourages Local Education Authorities to use ICT as part of the whole

learning package for children who are unable to attend school because of medical needs.'

It is helpful that Baroness Ashton chooses to emphasise this point, since we find that many Local Education Authorities still do not seem aware that using computers and the internet to assist sick children is recommended by the Government. Parents may wish to bring her statement to their attention.

Manchester University was recently commissioned by the DfES to hold three one-day regional seminars for Local Education Authorities to share good practice for the education of children unable to attend school because of medical needs. These have now taken place.

At each seminar there was a presentation by our partners Nisai Education to demonstrate how the virtual classroom can support the education of children out of school.



DO FAMILIES WANT PSYCHIATRISTS ?



The Young ME Sufferers Trust has received a grant from the Essex Community Foundation's Local Network Fund for Children and Young People, under their programme 'Children's Voices'.

We have for some time wished to seek the views of the children and families registered with us about the treatment to be offered by any clinics set up with the Government's new money for ME/CFS services.

We have also wished to know what you think about other potential services - not just those situated in a clinic - such as domiciliary visits for diagnosis, advice, help and care *eg* specialist nurses.

With our grant, we are undertaking an independent assessment in the geographical area in which the charity is situated. However, we began by seeking a 'thumbnail sketch' of the views of people throughout the country.

We asked a number of questions and gave you the opportunity to say more, if you did not just want to tick boxes. Your answers were most illuminating.

We can now reveal that 85% of families who have so far responded gave the thumbs down for the automatic involvement of psychiatrists in the care of children with ME. Yet this seems to be increasingly happening. If you have any experiences, good or bad, with child psychiatrists and their treatment of children with ME, please send them to us. The study continues, with Dr Nigel Hunt, so it is not too late to send in your green questionnaire.

Exploring: New Anti-Viral Drugs why not here?

Dr Elizabeth Dowsett, the consultant microbiologist who, with the exception of the late Dr John Richardson, probably treated more ME patients during her long career than any UK physician, explains.

ME is a complication of an infectious disease. If the virus gets into the brain it damages the nervous system *ie* the neurons.

The commonest cause of encephalitis (inflammation of brain tissue) in the UK is an enterovirus (gut bug). Polio myelitis itself was caused by three members of the enterovirus family, but there are many more enteroviruses against which we do not yet vaccinate children and these can cause similar symptoms to polio.

Once the encephalitis starts, it proceeds as any other encephalitis *eg* following measles, chicken pox etc. But one must distinguish between a viral and a bacterial cause.

The best prevention for ME is to use a rapid PCR system to diagnose an infection before the virus gets into the brain and treat accordingly – there are antiviral drugs specifically for enteroviruses in humans and animals now going into production.

These have been known about since the early 1980s. However, only now are they commercially viable. They are called capsid-binding compounds and they stop the virus getting to the brain.

In the USA, paediatrician Harley Rotbart, who is also a Professor of Microbiology, is working with a commercial company who is supplying a rapid PCR test (only five hours for the result).

Capsid-binding compounds go under different names in different countries. The US compound is called Pleconeril. They are not yet available in the UK.

The Young ME Sufferers Trust comments:

Unfortunately, once ME develops, these drugs will not cure the condition. But everyone who has suffered with ME will want to see these

procedures brought to the UK in order to help prevent others from suffering too. We recommend copying this article to your MP to alert him or her to what the UK could be doing and is not.

ME clusters occur in families, schools and communities. If the procedures described above were used early on, where serious infectious illness seems to be developing, clusters could theoretically be stopped in their tracks and brothers, sisters and friends could be spared the pain of an illness that is fast becoming preventable.

Misdiagnosis: New Canadian Criteria

Confusion and misdiagnosis is arising where the criteria used for diagnosis are not rigorous enough.

This is why The Young ME Sufferers Trust recommends the widespread adoption in the UK of the new Canadian diagnostic criteria

Developed especially for clinical diagnostic use, rather than for research, by a group of physicians who have seen over 20,000 patients between them, these criteria have been designed to prevent people who may have depressive or other illnesses such as borreliosis (a treatable bacterial illness formerly called pseudomonas) from being mistakenly grouped with people who have true ME.

The Medical Research Council confirms that there is no reason why these criteria should not also be used for research. *[We will be pressing for this. Ed].*

Find our full appraisal of the Canadian diagnostic criteria in our online collection of the Trust's key statements. *In the Spotlight : The Tymes Trust View* is at www.tymestrust.org/publications.htm

THE HOUSE OF LORDS LAUNCH of the TYMES Trust/NISAI Education Partnership

The Young ME Sufferers Trust specialises in the educational needs of pupils and students with ME/CFS. April saw a milestone in our work to help them. Could it help you?



Chair of Trustees Keith Harley and Jane Colby listen to Lord Clement-Jones

Lord Clement-Jones CBE, Patron of The Young ME Sufferers Trust, explained in his speech: 'It is now known that ME is more disabling than many other chronic illnesses, so perhaps it is hardly surprising that this illness is the biggest cause today of long-term sickness absence from school. This causes great educational deprivation.'

'Today we are all here to witness the start of a new partnership between The Young ME Sufferers Trust and Nisai Education. This partnership has the potential to revolutionise education for children with ME right across the country.'



Preya Thakrar and Russell Clark of Nisai talking with client Ben Bryant and his mum



The Honourable Frances Ommanney and Beverley Jameson, Expert Patient Scheme



Sophie Ellis got her GCSEs with the Virtual Classroom



Dhruv Patel, the brains behind Nisai Education



Trustee Margaret Ross presents Ursula Franklin with the Dr Alan Franklin Book of Remembrance

Such a simple idea, yet such a powerful one

by Earl Howe

Ask anyone to imagine having tea in the House of Lords, and they will probably picture something both calorie-laden and, in the best sense, quaintly old-fashioned. Those who gathered in the terrace marquee on April 26 to celebrate the work of Tymes Trust had exactly that delightful experience. There is something about a slap-up tea, with arrays of sandwiches, clotted cream scones and fancy cakes that restores the spirits from the word go, and this event proved it.

We were there to mark the launch of the Trust's wonderful new initiative, to deliver a virtual classroom to youngsters with ME whose illness prevents them from attending ordinary school. We learned all about it from the Trust's patron, Lord Clement-Jones, and Jane Colby, its Executive Director, and their enthusiasm was infectious. Such a simple idea, yet such a powerful one: to enable a child sitting at home in front of a computer, to talk to a teacher and be part of a classroom, just as they would do if they were actually in school - yet to go forward at their own pace. The Trust is providing this service in partnership with Nisai Education, and the results, by any measure, are spectacular.

Anyone looking around the marquee would have seen a sea of smiling faces, including those of parents, children and a number of parliamentarians who came to support the occasion. I am sure that the faces were smiling not just as a result of the tea or the glorious view over the river Thames. They were also a reflection of how positive we all felt about the work of the Trust, who are really making a difference to those young people whose illness puts them at such a disadvantage and is so often misunderstood.

We went away with a spring in our step. 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 Tymes Trust and their partners at Nisai, I am convinced that this aim will be achieved.

Jane Colby launching the partnership (top) followed by Lord Clement-Jones, Lord Colwyn, Earl Howe and Lord Addington discussing the project.





Bob Mills, Sky News Producer



‘Thank you very much for the opportunity to take part and also for giving me the chance to put some faces to names! It was a lovely day for me, overlooking the river on a glorious afternoon, topped off by afternoon tea on the terrace at the Houses of Parliament.

I have a feeling that the launch of this partnership and venture is the first of many big steps to tackling both the condition and - just as importantly - the stigma that up until now has been tied to it with a ball and chain.’

Chris Peachey Young Adviser

Keith Harley, Chair of Trustees



Trustee Alec Western. Alec’s daughter Victoria is a Tymes Trust Young Adviser



Trustees Sally Player and Jennie Whitlock



David Teece, Project Director, Nisai-Iris Partnership, Warwickshire Local Education Authority and Russell Clark



Patricia Noons, Dept of Health



Dr Jeremy Jeanes, Assistant Headmaster of Latymer School with Kerry-Ann and Michael Edge



Two former Headteachers, Alan Milward and Jane Colby discuss charity plans



Trevor Wainwright from Castleford Aid for ME



Dr Charles Shepherd, author of *Living with ME*

The launch of the Tymes Trust/Nisai Education partnership was a milestone in the care and education of children with ME.



Mark Colby, our web designer

ME is a potentially chronic, disabling condition defined by the World Health Organisation as a neurological disease (ICD10 G93.3). A bout of ME typically lasts some years, during which the child can be too sick to access education in the usual way. Nisai Education is supporting our drive to implement the e-learning and home-based learning recommendations for young ME sufferers made by the Chief Medical Officer's Working Group on CFS/ME, in which we played a major role, published by the Department of Health in January 2002.

The Report stated: 'An educational plan is not an optional extra but an integral part of therapy'. It recommended: 'Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning' and made clear that this may be needed on a long-term basis.

Crucially, it recommended that: 'In addition to the time of a tutor or therapist, this may require information and communications technology, which can also help improve social contact.'

The Department for Education and Skills endorses the Report and makes clear that children out of school through sickness are entitled to continuity of education similar to that in school. In 'Removing Barriers to Achievement', published in February 2004 the Government states: 'Some children [with Special Educational Needs] still face real barriers to learning...We are determined to transform their experience, working together with all those in the education service and their partners.'

ME can cause serious brain dysfunction and a greater level of disability than many other conditions. Therefore, providing education in the home can be a necessity, not an option. Research shows ME to be the biggest cause of long-term sickness absence from school, since exertion can produce deterioration. To protect children's health whilst also enabling them to achieve, modern technology, the internet, and visionary thinking have come together.

Our new report *Succeeding with ME* explains the 'virtual classroom' revolution. Learn at home whilst interacting online with a teacher and other pupils.

Bound report £6.00 from The Young ME Sufferers Trust.

Further information at: www.tymestrust.org/tymespublications.htm



Beryl Lockwood
Asst Education
Officer,
Warwickshire



'Thank you for taking the time to address the Scottish Parliament's Cross Party Group on ME and for not pulling any punches in highlighting the state of affairs as you see it. Your visit certainly provoked energetic debate, which is something that all Parliaments should encourage. Nowhere is that debate more urgently needed than in the field of ME.'

Alex Fergusson, Member of the Scottish Parliament
Convenor, Cross Party Group on ME

'This scheme will be excellent for young ME patients.' **Dr Nigel Hunt**



Alex Fergusson MSP with Dr Nigel Hunt

Seeing's Believing: Can the young zap the baddies?!

Visualisation is an ancient technique still used by Buddhists and hypnotists alike. In this technological age, people suffering from illnesses that have no ready cure are exploring traditional, non-pharmaceutical aids to healing. Dr Darrel Ho-Yen sent us his thoughts.

I was recently asked by a mother with an 11 year old son if he was old enough to try visualisation. I was rather surprised by this question as I had never considered age as being a major component in the use of this technique. I have always felt that the ability to imagine and to *believe* that the visualisation can work is the important factor.

Visualisation

As I state in my book *Unwind! Understand and control life, be better!!* people can visualise a giant eraser which slowly rubs out their illness. I believe there is also a need to develop a relaxation technique. This removes stress.

Some patients like to imagine fighting this illness, there is an alternative to using an imaginary eraser to rub it out. Instead, after slowly relaxing all parts of the body (foot, legs, abdomen, arms, neck, face) they then visualise a part of the body and use an imaginary gun to 'shoot' the infection. This can be a paint gun, a flamethrower or a miniature anti-tank weapon! In all cases, the mind focuses on areas of the body that are causing pain or other symptoms and tries to destroy the infection. People who do not like this idea can call on a superhero such as Superman, Batwoman or any other individual. One young child visualised his favourite pet dog licking away the illness.

Young people

Young people have vivid imaginations. Normally, I do not like patients using their imaginations too much as this is a great consumer of energy, so I advise restricting the use of television, music, videos and computer

games. Therefore I recommend that a visualisation technique, combined with a relaxation technique, be used for no more than three 20 minute periods in any one day. I believe this can be a useful way of employing the time one has to spare.

How did I answer?

My answer to the young mother was that I believed her child might be better at visualisation than some adults. Young children arguably have an even greater imagination than adults. I feel it is an important lesson for young people to learn a relaxation technique and the value of using the mind to help their bodies do the healing.

With so many baddies out there, the good guys need all the help they can get. I am very happy for the young to zap as many baddies as they can.

[My preferred method of zapping the baddies was to agree on a truce! Early tests having revealed that my own virus was Coxsackie B – a frequent culprit in ME and a relation of poliomyelitis – I explained to it that I was willing to give it house-room on condition that it didn't cause me too much trouble. Over the years, we've worked things out quite well between us. Ed.]



MODERN MAGIC : THE EVIDENCE

There has been a seriously mistaken idea that ME is 'all in the mind' when it is, in fact, 'all in the brain'. ME is centred in the brain and nervous system and its World Health Organisation classification as a neurological illness (ICD 10 G93.3) confirms this.

However, there is still a tendency to assume it can be treated *as if it were a psychological illness*, which leads to inappropriate physical demands on children by schools and others, often leading to relapse.

Visualisation, prayer, spiritual healing and other systems that are based on a strong belief in their powers are often used *to try and target physical illnesses*.

Magician Paul Daniels once demonstrated the power of belief in front of millions on television, by making his audience think that a crumpled up ball of silver foil was red-hot. It was comical to see grown men and women wincing and throwing it away, believing they would be burnt if they held onto it.

In April 2002, Thelma Agnew reported on the famous 'Placebo Effect' for *Health Which?* She wrote: 'Imagine being prescribed a course of pills made of sugar and paste. They contain no active ingredients that could possibly alter the course of your illness, let alone make you better. The dummy pills work a strange kind of magic.'

'There is, in fact, a great body of evidence to suggest that placebo or dummy treatments can sometimes work as well or even better than real medicines. Patients on placebos can even experience side-effects that mimic real drugs.'

'Nor is it just a matter of the patient responding to the illusion of treatment – objective measurements of symptoms such as blood pressure and post-operative swelling have found real physical changes.'

The House of Lords Science and Technology Committee found, in 2000, that 'the placebo effect is not just an imagined experience but can positively improve objective biological measures of health.' Patients with benign gastric ulcer in one study experienced a 45% response rate to dummy treatment, which was confirmed using endoscopy (a visual inspection of the inside of the stomach). Since then, an American study

has even suggested that the therapeutic effects of Prozac may be largely caused by the belief that it works.

Dr Michael Dixon, who wrote a book about this whole phenomenon, said: 'I see the placebo effect as the mobilisation of the patient's self-healing powers.' Science is trying to unlock the secrets of what happens.

There is a theory that the brain may be using a group of neurotransmitters called neuropeptides, triggered by feelings and thoughts. It is now known that the immune system receives a boost after happy experiences. Belief in the fact that a pill or a therapy can work reduces stress and gives a sense of relief.

So the encouraging message is that we have in our own bodies great power. We see it

So the encouraging message is that we have in our own bodies great power.

every time we cut a finger or a graze a knee.

If we break a plate, we must buy a new one. But, if the damage is not too great, we don't have to buy a new knee or finger – our body miraculously repairs the flesh and grows new skin over the wound – all by itself.

We don't need to make an effort to *believe* this. We take it for granted because we have grown up *seeing* that this is what happens when we cut ourselves. What might happen if we lost all belief in self-healing? How long would the cut take to heal up then?

Scientists seek reasons why belief may be able to help healing. But doctors must not fall into the trap of blaming those who don't recover – accusing them of having 'incorrect illness beliefs'. In bygone days people held that if you were ill it was because you had sinned. Not every old tradition is helpful.

Different illnesses may need all kinds of therapeutic intervention. But because of the evidence of our own eyes when a physical cut heals, we should never make the mistake of thinking that self-healing powers are only for 'unreal' illnesses. Quite the contrary. Science and the natural history of ME show that *we really can trust our bodies* to do their best for us, given time, love and care.

You Tell Us



Photographer Suzanne Greenslade has sent us a selection of her photographs. Suzanne has already exhibited in Spain and America, and she writes: 'I am sending you a number of images so that you can choose which ones you want to use for *Tymes Magazine*.'

Suzanne says the photos chart her own experiences over 4 years of ME such as loss, betrayal, isolation and finally rejuvenation. Her exhibition is called *Waking from the Long Sleep* and thanks to a grant from the Welsh Arts Council it will be at the Washington Gallery, Penarth in the Vale of Glamorgan from 19 September to 10 October.

If you are well enough, you are invited to the opening reception on Sunday 19 September from 3.00 – 5.00pm. Please tell Suzanne that you are a member of Tymes Trust.

You can contact Suzanne at www.suzgreenslade.com



Dear Jane

Thank you to Jennie Whitlock and yourself for the signed birthday card for Philip's 19th birthday. We have now become 'empty nesters'- our two sons are ready to lead independent lives.

We are particularly proud of Philip, who won the prize as best GNVQ Business Studies Student at sixth form college last year. He started the next level GNVQ and A/S level psychology in the autumn, but decided in January, with our full support, that he'd had enough of studying for the time being. This is partly because he did not really want to continue in a group of much younger students at college and felt he would like to move on.

Philip found a job with JD Wetherspoon through his own initiative, and is steadily progressing 'up the ladder'. The structured environment suits him, in spite of long and irregular hours, and he loves the contact with people. He has plans for his own flat, sharing with friends, and has his own car and all the necessary domestic skills.

Your advice has been invaluable over the last few difficult years. We wish your organisation well and enclose a donation of £20 as a token of our appreciation.

Regards, Philip's mum and dad.

Would you like to contribute to 'You Tell Us'? Young or old, send your stories to: You Tell Us, PO Box 4347, Stock, Ingatestone, CM4 9TE

Boundless

by Robin Sansom

How can I express this restless passion that I hide ?
This fairground of spinning thoughts and feelings that I ride,
Spiralling down and shaking me up,
Through joy and pain, through fear and love,
Dancing dizzily round and round,
The words are lost and make no sound.

How can I make clear the reflection on the waves?
Fragmented and confused is the image it betrays,
Tossed about and broken up,
Deep, deep down and up above,
Searching for something that's me,
The sun goes down, I cannot see.

But deep within a spirit lives,
Above all sound, beyond all sight,
It rises up this time again,
And lifts me high above my pain,
Where I am still and free from hunger,
In perfect love, in awesome wonder,
On blazing wings my heart takes flight,
Beyond the boundaries of my mind.



SEB'S MANOR



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

Sebastian says:

Just as well I'm generous, isn't it, guys? This page is fast becoming Cheryll's and Fudge's page, not mine at all.

Well, it's holiday time so I guess I could do with a holiday like other folks. Go, Cheryll. Over to you to do lots of the writing this time.

Seb

PS For our new members, Fudge is Cheryll's Tymes Trust Beanie Bear

I really would like to nominate my home tutor Mrs Wheeler for a certificate of Seb's Order of the Golden Web because she understands ME and has taught me so much in the two and a half years she has been my tutor. She will be leaving in the next few weeks but I have enjoyed her coming so much I will really miss her.

She has helped me in so many ways, even helped me to arrange doing part time work experience and helped me to be able to take my Art GCSE exam at home. She can tell when I need a break or if I am too ill to carry on. She makes the work I do really interesting. My favourite work I did with her was a story I wrote about my dog Tetley.

She has helped sort things out with school and has never made me feel guilty for being poorly, as school did. I will really miss her and so will my two dogs. Luckily she likes dogs too, even though she goes home covered in dog hairs.

I really think she deserves this award.

Many thanks

Cheryll Neyt



PS You remember her don't you, Seb, when I used to go in the front room to do my work and you and Fudge had to be quiet. Fudge sends her love.

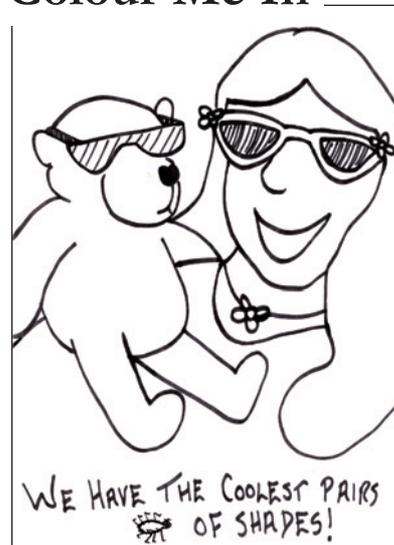
Do you remember our 'What makes me smile?' competition designed by Laura Shave?

This was **Anna Sheppard's** beautiful entry. One day Anna's mother was feeling a bit worn out so Anna drew her similar flowers in which to write all the things that made *her* smile. Guess what? It really cheered her up!



Why not draw your own, for someone you love to fill in.

Colour Me In



Drawn by
Laura
Shave

Mark in Ohio working on the car



Keep your heads up!
Best regards
Andy Wallace

American Le Mans Series drivers for Dyson Racing (2003 LMP675 Champions) gave Mark Colby these messages for you. If you go to www.tymestrust.org and click on the car you can get a close-up.

Hope the Hard Tymes are not too difficult to bear.
All best wishes
James Weaver

Sometimes it's endurance that counts. Never give up!
Your Friend
Butch Leitzinger



Cheryll and I were delighted to see such a lot of Fudge and Seb in the brilliant spring magazine. Fudge got very excited too, and is walking round the house thinking she's a super star and demanding a dressing room with champagne truffles to eat. She was also very surprised to read Matthew Eccleston's suggestion that she should be proposed for a Trustee and felt very honoured.

Best wishes
love Cheryll Julie and Fudge
((((waves to Seb))))



Email message:

I just wanted to thank you for my Beefeater Bear. Alas he arrived too late to save my chocolate buttons, but he was put to guard my chocolate eggs and so far has done a good job at keeping them safe!

Thank you,
Vikki George and Bob Beefeater

Vikki runs Post Pals - 'Posting a Smile on a Child's Face' at: www.postpals.co.uk



Hello Jane

Just to let you know that the lovely Beefeater Bear arrived today I have called him Max and he is feeling very important watching over all my unicorns.

Fudge liked him straight away and they are busy getting to know each other and I am delighted with his arrival. Please thank Mr Harley for me. Many thanks.



Cheryll Neyt



I just wanted to say thank you for my Beefeater Bear! I love him and he made my day when he arrived! I've called him Ben and he has really taken to his Superted duties (so far!) and it is wearing me out just watching him. I think he gets his energy from the same place as our puppy Havoc. I do wish they would share some.

Elle and Ben

Jane -

Look to your Tymes Trust account, you've another £60 donation coming in, cos they know what you do with it, and boy are they pleased when I can tell them.



Trev from Castleford Aid for ME

QUOTES-WE-LIKE

Kindly words are a
honeycomb,
Sweet to the taste,
wholesome to the body.
Proverbs

Our greatest glory is not in never falling, but in rising
every time we fall.
Sent in by Eleanor Ward

I live in my own little world - but it's OK, they know
me here.

Sent in by Chris Peachey, Young Adviser

Got a favourite quote?
Share it with us.
We'll put your name by
your chosen quote.

Education is the most powerful
weapon you can use to change
the world.
Nelson Mandela

YOUNG HEARTS

An invitation to you all from Jade Scarrott
whom we remember with affection



Dear Tymes Trust,

I have had ME now
for 4 years and I am
now 14. There was a
time when every day
was a struggle and I
can only imagine
what it must be like
for other kids like me
who have it worse,
where they can't get
out of bed or do
anything. I would like
to ask if all young

readers could gather any poems or thoughts
they have written, no matter how short or
long, and send them in so I can develop them
into a book.

Once this illness reaches your soul it
can make you feel the lowest of low. I would
love to make other people see this and 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 it first hand.

I really believe in this.
Love, Jade xxx

Photo courtesy of the Warwick Gazette

**Just before Jade's recent tragic death
in a road accident the Warwick
Gazette covered her project:**

*A young ME sufferer from Warwick is
compiling a book to help other young people
tell the world what the condition is like. [...] Jade
has had to be home-educated. But through her
darkest times she took to writing as a way of
expressing her feelings.*

*She told the Gazette: 'ME makes some
children so sensitive that they cannot even be
hugged by their loved ones and I can't even
imagine how painful it would be to see
brothers and sisters being held in their
parents' arms when they can't do the same.
Being so weak, I had no way of expressing
myself and it made me feel so small.'*

*The Young ME Sufferers Trust is
backing Jade's project and one of her poems
has already been published in Tymes
Magazine. **

Jade hoped to fill her book with the thoughts
and poetry of as many other young sufferers
as possible. Her family and Tymes Trust
want to make her dream a reality. Send
thoughts or poems to Young Hearts, PO Box
4347, Stock, Ingatestone, CM4 9TE or email
them using the contact form at
www.tymestrust.org

** Issue 45*

My Bedroom

Hi everyone at Tymes Trust!

I saw Eleanor Ward's email about her room and thought what a good idea it is and it would be really nice for all us kids stuck in our rooms to do. So here's my bedroom!



My bedroom is decorated to look like a rainforest as I would really love to be able to visit a rainforest one day. It's really interesting as you find something new to look at amongst the branches hiding under the leaves. I have a beautiful treefrog staring at me and a purple and blue spikey dragon lizard climbing a tree next to my door where a big colourful toucan is perched. In the corner is a stunning orangutan swinging in the branches. A snake is slithering down towards me with his tail coiled around the branch. Another frog watches me as I sleep. Spike, the iguana, is scrambling on the ceiling. There's a black jaguar asleep on a branch on my wall.



I've also painted lots of little 'Rockys' hiding everywhere. Rocky was my pet mouse and my best friend and always cheered me up and made my room defiantly the best place to be in because he was always there.

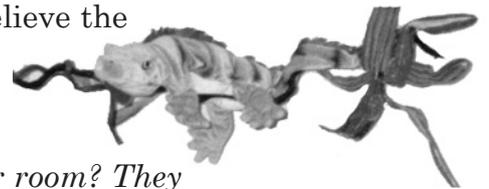


I also love to look out of my window and watch the birds and squirrels feeding from the bird table and feeder we have in our garden. They always make us laugh with their acrobatic antics!



Although I wish I didn't have to spend so much time in these four walls, at least having a fun and interesting room helps to relieve the boredom.

Tez Cabrera



Why not send us pictures of your room? They need to be good quality photographic prints taken on film, or high resolution digital images. If you are not well enough to take photos yourself, maybe a friend or someone in the family could do it for you?

JUST-A-POSTCARD

Just-A-Postcard : A Shirley Conran Top Tip

Keep a box of postcards ready-stamped, so you can easily write a quick note to friends. You can collect picture postcards or use blank cards that leave room for more writing. Shirley says: 'I always keep a box of stamped postcards handy.'

If you'd like us to send you a lucky dip picture postcard to use, send us a stamped addressed envelope.

If you'd like a bag of assorted picture postcards, please include a donation to cover costs.

Send to Picture Postcards, PO Box 4347, Stock, Ingatestone, CM4 9TE.



Simon Selkin's Big Box of Gifts

When our Executive Director Jane Colby met with big-hearted Simon Selkin at the Ideal Home Exhibition in London, the result was a Great Big Box of Gifts for Young People, donated by William Selkin Ltd. who were key exhibitors in the gallery.

To request one of Simon's gifts (suitable for either sex!) just send us a postcard telling us about someone who's made you happy – maybe they also gave you a surprise gift?

We'll print lots of your messages in the next magazine and we'll send your gift immediately – in fact, we'll go on sending them until we run out.

Send your request to Simon's Gifts, PO Box 4347, Stock, Ingatestone, CM4 9TE. Don't forget to include your name, age and address.

Non-uniform day – Dixie Grammar School

'Please find enclosed the proceeds of our non-uniform day. Thank you for your work with Elizabeth Colley – she seems much improved.'

Janice I Jones
Market Bosworth

Could your school hold a non-uniform day for us next term? All funds raised will go to services for young people with ME.

Shirley's Prizewinners!

Congratulations to everyone who entered the Shirley Conran letter-writing competition with such varied ideas. Shirley asked you to write to her about all the 'little things' that you enjoy. The youngest entrant was aged 11 years and the oldest is a member of our 26+ Group! A wonderful spread.

Our thanks to Shirley for donating £100 for the prizes. We will be printing selections from your letters in the next magazine.

