

The Young ME Sufferers Trust

2010-3

£3-95



The Queen's Award  
for Voluntary Service

The MBE for volunteer groups

# Vision

for young people, families and professionals



## INTERVIEW SPECIAL

Dr Nigel Speight on Treatment  
BBC Radio : Professor Jill Belch and Jane Colby

## THE BRIEF QUESTIONNAIRE

Are schools failing children with ME?  
Please send us your experience

## LAUNCHING OUR YOUNG HEARTS AWARD

View in full colour at [www.tymestrust.org](http://www.tymestrust.org)



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## THE YOUNG ME SUFFERERS TRUST

*Registered Charity Number 1080985*

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*Cover : Unexpected X-Factor groups winners*

# Our Patrons



Lord Clement-  
Jones CBE



Earl Howe



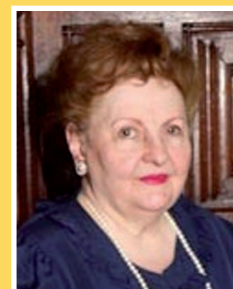
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OBE



Lady Elizabeth  
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The Countess  
of Mar



Princess Helena  
Moutafian MBE



Terry Waite  
CBE



Barbara Windsor  
MBE

# Vision

When, during 2010, we were given the Queen's Award for Voluntary Service, it was for pursuing the educational rights of children and young people with ME, and advancing their care.

## Discrimination

There are times when we team up with other organisations on certain projects and other times when we must be prepared to lead the way and, if necessary, stand alone. I have been personally outraged at two unwelcome developments this year against which the Trust has stood out. One of these has been in education, where children with ME continue to be discriminated against.

As Jane Colby, our Executive Director and a former head teacher has often said, when a child has ME it's not enough to tinker around the edges of education, you need to make substantial changes in order to protect their health and help them achieve whilst recovering.

Many children with ME do better studying at home, yet we have seen child after child being turned away by exams centres (schools and colleges) after they have studied all year for public examinations. And this refusal comes despite such provision being a duty of Local Education Authorities. Often, institutions that do agree to host the exams try to charge exorbitant fees. This is plain wrong.

Our Young Advocate, Shannen Dabson, and her family have been busy researching exams centres and the Trust now provides a letter you can send to your own school, inviting them to become a host school and help end this discrimination. Should they accept, they will receive a Young

Hearts Award to recognise their contribution. Details are in this issue of *Vision*.

## Parliamentary Question

In our work with the Nisai Virtual Academy to provide virtual education in the home for young people with ME - something that has now led the Academy to appoint its own new teachers and train them in-house - we have seen great successes, but recently problems have arisen with the agency that took over from the Learning and Skills Council, which we are also pursuing. A parliamentary question has been tabled on our behalf (see page 4).

## Unethical Research?

We also felt obliged to make a public statement, in which we were joined by the ME Association, against the proposed research on children with ME using the Lightning Process, a psychological programme that has had many Advertising Standards Authority judgements against its unsubstantiated claims.

In accordance with published ethical principles, research should be done on adults before children, who are vulnerable and protected by law. Many people are reporting eventual deterioration from undertaking LP.

## 'Children should not be used as guinea pigs'

Professor Robin Gill (a member of the British Medical Association Medical Ethics Committee) expressed that view in a letter to the *Church Times*. He states that those who object that this study is unethical are 'surely correct'.

We understand that the feasibility study outcome measure - to which



*Keith Harley*

we strongly objected due to its potential for pressurising children into school attendance and away from other forms of education to which they may be legally entitled - was changed and the study approved. However, we remain concerned. As I write, the National Research Ethics Service is conducting an informal review of the ethical approval.

As always, don't hesitate to phone our Advice Line if we can assist you in any way.

Keith Harley  
Chair of Trustees

## Forward ME

The last meeting of the Countess of Mar's group 'Forward ME' discussed the controversy over the proposed LP research.

One justification for studying children is that the condition to be studied does not occur in adults. It was drawn to the Group's attention:

*that Dundee University (in a biomedical study co-funded by Tymes Trust and MERUK), had discovered the same abnormalities in the blood of children that they had previously found in adults. Tymes Trust stated that this shows that ME in children was clearly not a different illness from ME in adults.*

[www.forward-me.org.uk](http://www.forward-me.org.uk)

# Patrons of the Trust



**Founder Patron  
Lord Clement-Jones CBE**

I am always inspired by the spirit of endurance

shown by young people with ME, and your determination to overcome obstacles that this dreadful illness places in your path. All of us can become discouraged at the size of the tasks we face, but ME places a huge burden on families, and those going through the worst of ME need to know that others care, so it's particularly pleasing to see the new Young Hearts Award made available for you to recognise people who have helped you.

I am so pleased, too, to welcome two more Young Officers to the Trust: Sarah Coulbert and Jen Flynn. They are our Young Photographers, and in this issue of *Vision* you can see how they look at nature. Try and spend some time contemplating these beautiful images they have sent for you to enjoy [pages 22-23].

I want to reassure anyone thinking of volunteering as a Young Officer of the Trust that Jane and her Team will take care never to ask too much of you - in fact, I'm told that what our Young Officers do is usually all their own idea, carried out when they want to do it. That is extremely impressive. They are not usually appointed just in order to do something for the Trust, but on the strength of something they have already done from their own initiative, like Shannen Dabson, our Young Advocate, and Jozef Mackie, our Young Spokesperson.

Shannen is still helping to encourage schools to host examinations for students with ME who are studying with the Nisai Virtual Academy so you may wish to join the campaign by sending out the schools letter that the Trust provides [page 19].

I send you all my best wishes for a good 2011.



**Terry Waite CBE**

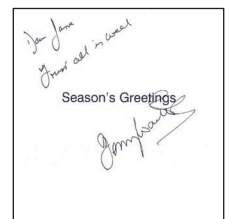
On 29 November 2004, Terry Waite launched *Young Hearts*, our collection of poetry by children and young people

with ME, inspired by Jade Scarrott, a 14 year-old with ME. That day became Young Hearts Day, an annual occasion when the Trust remembers children with ME everywhere. This year we have launched two campaigns which you can join [page 19 and back cover].

In his forward to the book, Terry Waite writes: *Life is not fair and often we cannot understand it. 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.*

Turn to this book for inspiration and to show others the spirit of young people with ME.



## **The Countess of Mar Parliamentary Question**

Local Education Authorities fund the Nisai Virtual Academy courses for under-16s.

Despite a recent administrative hitch in funding for over-16s (caused by the YPLA's embedding within LEAs) the Academy has limited alternative funds for over-16 courses. To secure a place, call 020 8424 8475 as soon as you can.

### **The Countess of Mar asked Her Majesty's Government**

*how they plan to protect the funding for virtual education courses*

*for young people over the age of*

*16 with myalgic encephalomyelitis/ chronic fatigue syndrome which were previously funded by the Learning and Skills Council through the Nisai Virtual Academy, given that the Young People's Learning Agency refuses to recognise the Nisai Virtual Academy as a provider while Local Education Authorities providing education for under 16s do recognise the Academy.*

### **Reply, Lord Hill of Oareford**

*The Young People's Learning Agency (YPLA) has informed the Department for Education*

*that following the receipt of an application from NISAI Virtual Academy (on 28 September 2010), the YPLA is currently considering NISAI Virtual Academy as a new provider through its process for considering new Independent Specialist Providers for learners with learning difficulties and/or disabilities. It expects to make a decision by next Spring.*

*In the meantime young people are able to access provision from the NISAI Virtual Academy via an arrangement with Harrow College, which is funded by the YPLA.*

# what Nigel thinks



**Consultant Paediatrician Nigel Speight and Jane Colby have worked together for almost 20 years, lecturing at conferences and working on committees. Recently retired, Nigel frequently accepts locums and is active on The Young ME Sufferers Trust Professionals Referral Panel.**

*Nigel, we've worked together since way back, haven't we?*

Well, what we're still doing is helping to support and protect families who are suffering from disbelief and the various results of that.

*And when we started working together in the early 1990s on the ME Task Force, and then on the Chief Medical Officer's Working Group Report, they were even suffering from it then.*

Yes. I'm never sure whether things are getting better or worse. Obviously I hear the hard luck stories but they're still happening. I've seen a number of cases of threatened care proceedings in the last couple of years.

*You're on our Professionals Referral Panel so you're happy to talk to GPs and paediatricians to help clear up that kind of misunderstanding aren't you?*

Well, naturally I don't like sticking my nose in, but I do talk to families and I always express a willingness for the GP or paediatrician to phone me, and sometimes they do and sometimes they don't.

*We get the same thing with teachers. Sometimes they do, sometimes they don't. I often find when they do, it's really very helpful.*

Absolutely. It's a very good sign if they're open-minded enough to phone. It's always very encouraging.

*I don't know whether you would agree with this from your experience, but we find that one of the main triggers for these accusations seems to be that the children aren't in school, and with ME children may need to take quite a long time off school.*

Well, obviously education generates some of these, especially if they

of not having experienced what an unpredictable condition this is and how severe it can be.

*Yes, I was going to make that same point. You get cases where schools and doctors are very sympathetic to start with but they simply can't believe that it could go on for so long or that it could be that severe.*

Right. There are so many different levels of disbelief. A psychiatrist once said to me that he could believe it could last for about six

months but after that, it's abnormal illness behaviour. Hopefully, not many people still believe that, but he said it very openly and honestly. Lots of people believe in it as a relatively mild condition and then begin to lose patience.

I think the other thing for the doctor in charge is that, when the patient gets

worse, it really hits a panic button. You begin to think you've missed something or you've got something wrong and if the worst happens you'll be blamed. And that can lead to doctors over-reacting.

*I suppose the tragic thing is that if they do over-react, it can lead to something that makes the situation even worse.*

Absolutely. It's weird - the professional can't tolerate the illness



*Dr Nigel Speight at the Nisai Education/Tymes Trust Learning Commitment Awards, House of Lords, ME Awareness Day 2010. With Trevor Wainwright, Jane Colby, Education Minister Earl Howe, Lord Clement-Jones CBE, and Dr Andrew Easton*

don't have the protection of a diagnosis. The education system just naturally leads to pressure.

The other variety I see is the case that is tolerated for a year or two, but if the child gets much worse, this seems to rattle the professionals and they don't seem to believe that ME can be so bad if they've never seen a case of severe ME before. They begin with disbelief again, having believed it up to then. And sometimes it's a matter

when the young person and the family are actually doing their best to tolerate it. I remember when a GP was so upset at a severe case that she came round once a week to discharge her grief on the mother and the mother couldn't take it any more and had to ask her to stop coming!

*Oh dear! Actually, we had the same thing with a school, where a child said, 'Will I be well enough to take my exams next year?' and the teacher said, 'Of course you will'. Because she couldn't face the idea that it might be something that wouldn't happen in that time-scale. That came out when I was giving a lecture. I explained that when somebody asks, 'Will I be well enough to take my exams?' they want the truth - they'd rather hear, 'Well, you may be, and that'll be great, but if you're not, there's lots of other things we can do to put special arrangements in place.' Including taking the exam at home. They want the truth.*

It's like doctors used to be with cancer. They couldn't face up to it, they couldn't talk to the patients about it and they used euphemisms and left patients high and dry because they couldn't be honest with them.

*This is where I worry about the NICE Guidelines because I don't think they truly give a proper picture of how severe this can be with children.*

Yes. I just don't see why the CMO's Report wasn't exploited more and

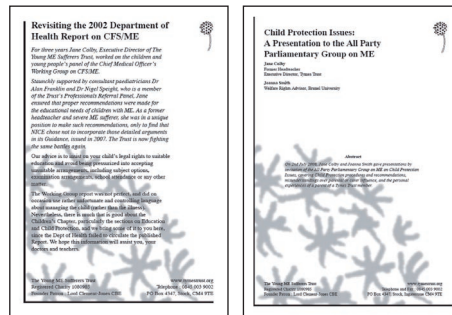


*Nigel and Jane on the MEA Question Time panel in Cardiff, hosted by WAMES, a Tymes Trust Partner Group, in October 2010. With Dr Charles Shepherd and NHS dietician Sue Luscombe, Jan Russell, WAMES*

believed more. It wasn't circulated enough. It should've been the last word. In the NICE Guidelines they should've listened more to the patient organisations.

*Quite. As you know, we've put together a little booklet with essential quotes and information from the children's chapter of the CMO's Report which you and I helped to write.*

Yes.



*And we've got that for anyone - it's free on the website. We're also concerned about another problem that seems to stem from the NICE Guideline. There's a myth going round that you only recover from this illness if you're treated. Clearly, that's rubbish.*

**I think the belief in 'treatment' is currently the single biggest problem**

I think the belief in 'treatment' is currently the single biggest problem. Lots of these centres have set up. And local champions - whether it's a local paediatrician, a therapist or whatever - seem to believe in their own treatment too much. Whether it's CBT or graded exercise, pacing, colouring things in, whatever it is, they seem to believe in it. Then it really upsets them if someone gets worse despite their best efforts. Sometimes they get worse because of their efforts, pushing them too hard. Sometimes they just get worse and it's not the fault of the treatment. But the doctor can't tolerate

it. I've seen care proceedings initiated just for that reason. The paediatrician had allegedly guaranteed the family a hundred per cent cure rate, which she said was following NICE Guidelines.

*Well that's really worrying. I'm a perfect example of what can happen without treatment. On a good day I can go round a golf course now and I never had any 'treatment'. In the end you begin to realise that what Dr Dowsett said all those years ago was absolutely right - that the body is trying to heal itself, and a lot of the time you're better off avoiding people doing things to you, and let it get on with it.*

Yes, I've never promised patients any sort of treatment. I have very grateful patients just because I haven't promised them the earth. But you see, doctors who believe in their treatment are like First World War generals who believe in their plan. When the plan fails, and the men are all massacred, the generals have to say it's the men's fault for being cowardly. Blaming the victims for the failure of the treatment is tragic.

I think of the motto, 'Beware of what you wish for.' People demanded treatment and after the CMO's Report we started getting people who believe in their treatments.

*This is why we're very concerned with this whole push to try to get clinics. Because until it's properly*

**Doctors who believe in their treatment are like First World War generals who believe in their plan**

*accepted by the medical establishment that we're looking at a serious physical illness - and probably a viral infection which needs proper anti-viral treatment and that sort of thing - you are going to get the wrong sort of clinic if you push for them.*

A lot of local centres have been set up. Some are supportive - I've always said the

most important thing was for a family to get support and protection and help with practical things. But this belief in treatment - well, the word is not appropriate for ME. You can talk about management, but we don't have a cure, and to start talking about treatment leads to people being blamed when they don't get better.

*We agree totally about this, which is why we work so well together, Nigel!*

You know, I thought when I retired I'd be able to leave ME to the next generation, but I've recently been asked to be medical adviser for two adult charities. I'm a paediatrician, I shouldn't have to do that but of course I agreed.

*I can understand why. We're holding the fort aren't we? Firefighting. Until people finally accept what the illness is.*

Yes. And we're awaiting reinforcements!



**I am twenty three years old,** and have been diagnosed with ME for six years. I am housebound most of the time and find day to day tasks impossible sometimes. I would like to honour my sisters, and my Mum and Dad.

My sister Iona, who is now 16, has helped me so much the last few years. She often makes my meals, changes my bed sheets, and helps clean my room and do my washing, even though she is

very busy with her school work she always makes time for me, and at times I would never have gotten out of bed without her.

My Mother, Fiona, orders and picks up my prescription, and accompanies me to all of my appointment even though she is very busy.

My father, George, has always encouraged me to do my art. I had to leave school at seventeen, and didn't get to go to University. Because of his belief in me, and help, I now have a book published, and two others on the way. He changed

the spare bedroom into an art room for me, and bought a special table for me when I was mostly bed ridden, to do my drawing in bed.

My sister, Sealy, 21, is living the life I thought I would get to have at University. She is always so positive and helps me to live a life a 23 year old should, although only once every few months, and go out to a party and have fun. Without her I would never have the confidence to do anything like that, and I know she will look after me if I go out. She sends me Gluten free food from the mainland (I live on an Island

in Scotland) and always find time to and makes it a high priority. My sisters are my best friends, maybe even my only friends since I became ill, and I want to show them how much I appreciate all they do for me, and also my parents.

Without my family I can't even bear to think what my quality of life would be like, I'd probably be in hospital, or extremely depressed and lonely.

Please let me know how I can get four certificates for them.

Thank you in advance,

Hannah Titania Middleton

**I'd like to honour** my lovely GP, John Anderson, who has been a massive support, visiting me every 8 weeks throughout my whole illness (17 years) but sadly is retiring at Christmas.

Thanks for all your hard work.

Take care  
Love Amy Scroggie

**In the Young Hearts Day Alert** you said that there are certificates available to thank carers. I was wondering if I could have three, so I can properly thank my Mum, Dad and Aunty for caring for me. My mum gave up her life for over four years to be with me and I will be eternally grateful.

Thanks for all the work you do at Tymes Trust. I have been really blessed through your magazine over the last year and a half.

Hannah Carling



**Don't forget to ask us for a free Young Hearts Award so you can honour someone with a big heart! No-one is too old or too young to ask.**

*Whenever you write in or email us, don't forget to say if you'd like to be quoted in Vision. Send us a photo as well if you can!*

# WHAT HAVE YOU BEEN DOING?

My daughter Kirsty has been a member for a few years now, and has enjoyed reading your magazine and just knowing she wasn't alone with this debilitating and misunderstood condition. Her condition has improved massively over the last eighteen months, and despite missing three years of school, managed to sit 6 Scottish Standard Grade exams. After a nervewracking wait the results came through - we had no idea what to expect as Kirsty had never sat any secondary school exams

before - and to her delight she passed them all, three at Grade1(A) and three at Grade2(B)!! At times in her illness she could barely read and couldn't write more than a few words and I wish we had known then that this day would come. We know she is not out of the woods yet and her health will have to be carefully managed, but this has given her confidence a much needed boost. I'm sure you can imagine how proud and relieved I am!

Doreen Cumming



*Doreen is our newest Advice Line Team member. Kirsty has had a little setback recently and we all send her our love.*

I wanted to share with you what's happened in my life over the last 8 years. When I was 15, I was diagnosed with ME. Although this did limit what I could do and I would say I had ME, I don't really believe I fully accepted it. I was always worried they had misdiagnosed me and I didn't talk about it much. It did limit my schooling and I missed quite a lot of my GCSE years but I always caught up the work.

School weren't outwardly horrible to me but it was like they were saying 'not you again'. I completed my GCSEs with special consideration. I went on to do A levels but had to drop History after the first year as although I had been good at it before I could no longer piece information together in my head!

I carried on German and Chemistry to A levels and passed. It wasn't easy during those years as my teachers (mainly for

German) didn't understand and made it very difficult for me to ask to leave, which got me quite stressed about it. After finishing my A levels I caught a cold in the November which sent me to bed. I stayed there for the next four years and four months.

During the last year and a bit I signed up to TYMES Trust and it was the best thing I did. I felt like I wasn't on my own and I was so happy when Vision printed a poem I had written. I started to accept I had ME.

I prayed honestly to God - not something I'm always good at - and told him my motives weren't entirely pure as some of it was that

I wanted proof He was there. That night I woke up after a dream where I reached out to take something from mum. I felt tingling and warm. I have never felt anything like that before and I instantly felt something had changed. The next day I told my parents. I began sitting in a chair

My pastor came to see me and I told him what had happened and talked through some things. I'm not, I must add, brimming over with faith, I trust God but I am just like everyone else and I struggle. The last few months have been full of firsts.

produce them miles faster than before! Thank you so much for the work you do and I would very much like to stay a member of TYMES Trust if that is ok.

Hannah Carling  
*It's good to hear from those of you who have been with us for years. Everyone is different. We appreciate it when you share your thoughts and talk about what helps you in your own life.*



*At Buckland Beacon on Dartmoor. Hannah says, 'The ten commandments are etched on stones at the base.'*

It is a big change to get used to and I am finding it difficult, but I feel that God is helping me and I know I will get through.

more and then I knew something was different as I had been trying to do that for years!

At the moment I am making cards and I intend to have a sale to raise money for TYMES Trust in the New Year. I can now



Before my daughter Catherine became ill she started to buy the wonderful world of teddy bear magazines. With the issues came a number of teddy bears and the materials to make them clothes. They also provided a number of accessories. I have just finished Harry who is set to go on his hols. He is about 8" high and has a set of clothes and camera etc. I wondered if perhaps one of your younger members might like him - perhaps he could be used as a prize? I would just like to find him a home.

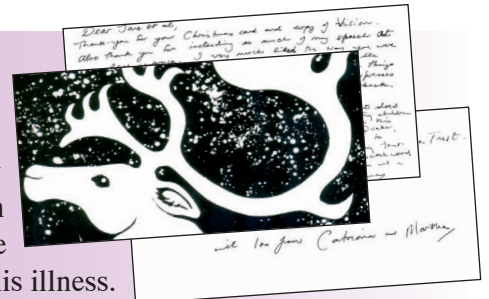


I have found a photo of Catherine and myself which was taken several years ago. The metal dog I am holding was a birthday gift!

Barbara Milsom

*We can always find teddies a good home! Thank you Barbara.*

Can I say what a wonderful job Tymes Trust does - to have this caring, intelligent, indefatigable charity representing children with ME with integrity is a huge support to all of us with this illness.



I attend Quaker meetings. An early 17th century Quaker, Margaret Fell, described the duty of Quakers to 'speak truth to power'. I feel this is certainly something that you do and I honour you for doing it. It is a good watchword for us all.

Catriona Courrier

*Letter in the Flintshire Gazette*

It has recently been brought to our attention that there is a lack of provision [...] for children with ME in North Wales, so the Clwyd ME Support Group is now going to campaign for a clinic.

Barbara Turnbull, Chairman

*Barbara would like families in the area to contact her, to ascertain numbers and discuss the children's needs. However, the Trust advises caution about 'treatment' until the aetiology of ME is established. Please see Dr Speight's interview on pages 5-7. Clwyd is a Tymes Trust Partner*

### Pensioner's bid to help young ME sufferers



**CAMPAIGN:** Barbara Turnbull of Conrath's Quay is starting a petition to get the NHS to open a specialist clinic for children with ME in North Wales. **By Dave Goodban**

Barbara Turnbull, who lives at Conrath's Quay in Flintshire, has started a petition to get the NHS to open a specialist clinic for children with ME in North Wales. She says she has been campaigning for a long time and has now reached 100 signatures. She says she has been campaigning for a long time and has now reached 100 signatures. She says she has been campaigning for a long time and has now reached 100 signatures.

*Group. We know that Barbara is keen to see the children's education properly supported and the Flintshire Chronicle also covered her initiative.*

[clwydme@googlemail.com](mailto:clwydme@googlemail.com)

*In 2008, Eleri Messenger made some beautiful miniature Christmas cards, featured in Vision. We saved them up for something special. Well, this year the Ipswich and Norwich Co-op Foodstore hosted a collection box in aid of the Trust. It was a brainwave*

*of Barbara Robinson who organised it as a surprise! Thank you Barbara. We received £143.00 and we sent one of Eleri's handmade cards to the Manager and his staff along with our letter of thanks.*

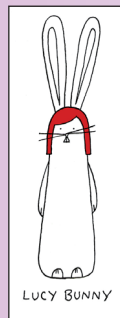


Firstly, CONGRATULATIONS! on the award of the MBE for groups! Very thrilling. I enclose the greetings cards for you as promised - there are TWO large packages of them.

Rebekah Alexander

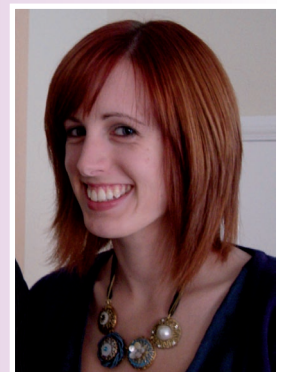
*If you have had a nice greetings card with a message from Anita this year, the chances are it was donated by Rebekah!*

*Lucy fought ME in her teens. She sent us her latest project: www.hoppybunnies.com! The website says:*



Hoppy Bunnies is the brainchild of

Lucy Player, a graphic design graduate from Essex with a slight obsession for drawing bunny rabbits...



Thank you for my pens. They are fab!

Love From Isabella

*Isabella tested out our store of 'magic' pens to make sure they're still working ok. They are!! The white pens change the other colours. To get yours, colour Susie's cosy fireside on page 12.*



# Meet the Team

## Introducing Anita Williams



*Anita with her daughter Isabella*

Hello I'm Anita and have been helping Jane with various administration jobs since the beginning of the year. I first heard of the Trust last year when it was one of the charities chosen

to be awarded money as part of the local Waitrose monthly charity donation scheme.

The timing was perfect as I was looking for some voluntary work, which fitted in with being

a Mum to Isabella, but wouldn't jeopardise my health. Having suffered from ME for 15 years TYMES Trust seemed very relevant and something I could relate to.

It is great to be part of a charity that helps provide

families with support and information on an illness that is not widely understood.

*Anita is being too modest! She has become a much needed part of our Team and you may have received one of the friendly notes she is frequently called upon to write to members.*

*She has also been sending out prizes recently... have you received one? If not, turn to Seb's Comp, or Things 4 U 2 Do. We have been given lots of new prizes (some from Isabella and her Dad!) and Anita's waiting to send them out!*



*Anita wearing a necklace of silver hearts on Young Hearts Day at the Chelmsford Council for Voluntary Service (with BBC Essex editor Gerald Main)*

## Jo's dad inspires Young Hearts Award



*Jo-Anna with her father Barry Cripps*

We were all so sad to hear of the death of Jo-Anna Roberts' dad. Jo-Anna is our Advice Line Team Coordinator and for many years she has had ME. Her dad took a turn as a member of the Team as well. To commemorate him, we've inaugurated a Young Hearts Award for people who give help and support to our members, just as Barry

## Jennie Whitlock



did when Jo-Anna was so ill during her teens. We liked these words from the poem Jo-Anna sent us: 'You can turn your back on tomorrow and live for yesterday, or you can be happy for tomorrow because of yesterday.'

You can nominate your mum, dad, gran, or anyone who has been really helpful and supportive to you, for a Young Hearts Award certificate. See back cover.

Jo-Anna said;

*The certificate is lovely - really bright and bold - I'm sure it will put a smile on a lot of people's faces! I love the text too - it's just right - a great way to spread some good feelings. It's really nice to know that people will do this in Dad's memory. Thank you.*

You may remember that Jennie had a bad road accident in 2009, when someone drove into her car. She sends you all her love and says 'thank you' to those who have asked after her.



*Thank you for inviting me to Ingatestone Hall. I had a great time. Love Isabella x*



*from Nigel Hunt.*

## Dr Nigel Hunt

*Seasons Greetings and Best Wishes to everyone*

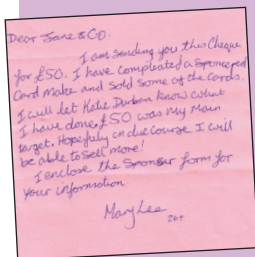
Dr Nigel Hunt is a

GP with experience of severe ME cases in his work. He is part of our Professionals Panel and has been advising us on the financial position with regard to ME clinics and what patients want.

# Fundraising - Many Thanks!

Friends Co-ordinator Katie Durben interviews Mary Lee

*I asked Mary Lee, who is a Friend of Tymes Trust, to tell all of us about her own experience of the Friends. Mary has become quite involved. She has made cards as a fundraising idea this year and has another Friend as a pen friend. (The Friends can have pen friends if they like and in Mary's case it's me!)*



*Did you enjoy fundraising for Tymes Trust?*

Yes. Art work is something I enjoy so making the cards was fun and relaxing. Selling them is a bit harder.

*What exactly did you do?*

I had lots of card and things I had been given, so using those and old cards I had received I made cards for different occasions.

*And what did you get out of it?*

A lot of enjoyment, and raised money for a good charity. I am a voluntary youth and children's worker

and feel it is important to support this charity for young people.

*How much did you raise in the end? I have you down for £50?*

Yes, I raised £50 pounds from sponsorship for making the cards and selling some.

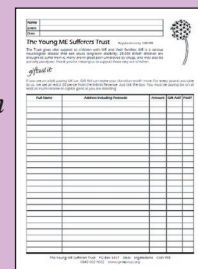
*Do you want to add anything, about the Friends?*

The Friends? I feel being a part of this helps us to look at ways of raising money but that is not all. I now write - and Skype - you and enjoy our communication. We have become friends. And it is a great way to support Tymes Trust.

*Katie would love to hear from you. Let her know if you'd like a penfriend from among the Friends.*

*There is a sponsor form you can print out at [www.tymestrust.org](http://www.tymestrust.org) (on the donations page) if you need one.*

Katie Durben  
Friends Coordinator



## A Day in Westminster

*Janice and Bill of ReMEMber amused us with a 'Samuel Pepys' historical account of their day with the Trust in the House of Lords*

*earlier this year. Here's an excerpt...*

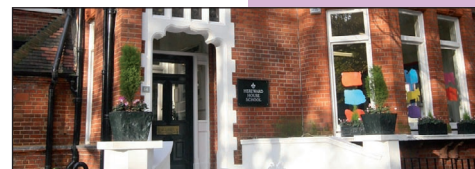
Up betimes and my wife and I did hie us unto ye Palace of Westminster there to attend a reception by ye TYMES Trust which doeth good work for ye children afflicted with ME. [...] We were summoned to Black Rod's dwelling in Westminster Palace, there to eat sumptuous foods and drink delicious tea (a new, expensive drink from China) and behold an excellent presentation from the TYMES Trust.

First my Lord Clement-Jones, our host, did give an excellent address telling us of the work of the TYMES Trust. There was then a recorded message from Lady Elizabeth

Anson, the Queen's cousin, who has had ME. Then Mistress Jane Colby spake about Learning Beyond Boundaries, a system that enables disadvantaged young people, including those suffering from CFS/ME, to pursue their studies at home. And this they do with the help of a device called a computer, which enables them to take part in live interactive sessions, lessons, tutorials, group activities and I wot not besides. And they are able to do these things in their own time. 'And,' saith Mistress Colby, 'this system is less expensive than a home tutor.' She then presented the Learning Commitment Awards to young people who had made great progress using the system.

And in sooth, it had been the jolliest day I can recall.

*With thanks to reMEMber Magazine, June 2010*



Hereward  
House  
School

We would like to express our sincere thanks for their generous contribution of £1000 to the Trust's work.

Because our whole team donates their time, the entire amount will be used for services to children and their families.



# U 2 Do

Susie Jayasinghe is back to warm you up with a special seasonal colouring

## Things 4



COLOUR THIS COSY WINTER SCENE AND SEND IT TO US FOR A PRIZE. COLOUR A PHOTOCOPY IF YOU DON'T WANT TO CUT UP VISION. WE'LL RETURN IT IF YOU SEND US A SPARE STAMP. WIN A SHIRLEY CONRAN WRITING AWARD BY INVENTING A STORY ABOUT THE PICTURE.

HOW OLD ARE THE CHILDREN? WHAT STORY IS THEIR GRANDMOTHER READING OUT? WHAT IS GRANDAD

TELLING THEM ABOUT? NO-ONE'S TOO OLD OR TOO YOUNG TO JOIN IN OUR ARTISTIC AND LITERARY ACTIVITIES!

### SUSIE'S COSY FIRESIDE

NAME
AGE
ADDRESS

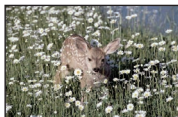
# Winter Wood

As the snow came drifting down  
 We left the bustling shops of town  
 And wandered through the winter wood  
 All wrapped in gloves and scarf and hood

The flakes fell softly through the trees  
 The snow came almost to our knees,  
 And soon we found, all tucked away  
 A lighted house, as bright as day

Its windows shone as darkness fell  
 But who lived there? We couldn't tell  
 And then we smiled, for we could see  
 Their tinselled, lit-up Christmas trees

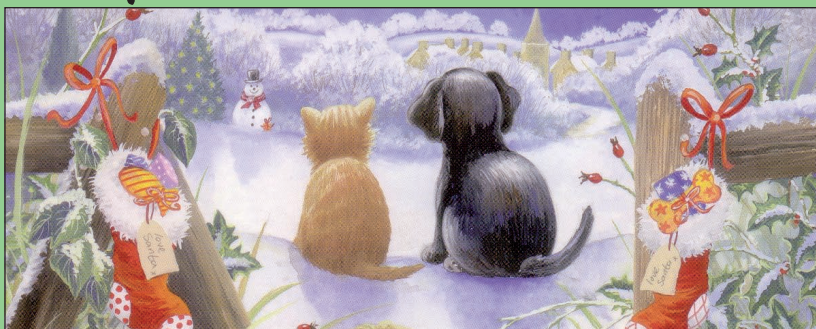
Fill in the missing rhymes for a prize - one letter for each dash. First correct entry wins a beautiful 2011 baby animals calendar, personalised with your own name. And who lives in the house in the wood? Tell us the story to win a Shirley Conran writing prize.



Winter Wood picture drawn by Yvonne Arber

# Mitsy and Scruff

February 2011						
Sun	Mon	Tue	Wed	Thu	Fri	Sat
31	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	1	2	3	4	5	6



Two pets found a snowman  
 With a black top hat --.  
 'Hmm,' said Scruff, the puppy  
 'I could do with that'.  
 They they saw the snowman  
 Had a bright red scarf ---.  
 'I want that,' said Mitsy.  
 'Ha! Don't make me laugh!'

'You'd look stupid wearing that!'  
 'Well you'd look stupid in a hat!'  
 All the time the snowman  
 Grinned and watched the pair  
 While the bells of Christmas  
 Echoed through the air --.  
 'Have a good New Year,' he called  
 'And no more scrapping. I'm ap ---!'

# HO HO HO LABELS

We'd like to thank our members for this idea!

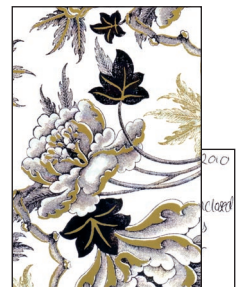
Send us a donation and we'll send you some self-adhesive Ho Ho Ho labels for your cards and letters. Labels read *Ho Ho Ho! We're supporting The Young ME Sufferers Trust.* Tell us how many you'd like.



We've also got teddy labels and flower labels to use throughout the year.



Please find enclosed a £15 donation towards my labels. Thank you for your help sorting them out. Kind regards always, Suzie Henson-Amphlett



Suzie is preparing to join our Advice Line Team. She and her family were with us at the House of Lords.

kind regards always  
 Suzie H-A



Send us the missing rhymes and we'll send you a cuddly little snowman from Mr Harley's menagerie! He always provides seasonal gifts for you.

# CHALLENGE JANE!

SEND HER PICTURES FOR POEMS

You wouldn't believe how long Jane took to choose two pictures out of all the cards you sent last year to write about.

We display all your cards and it always looks very festive here.

Yvonne Arber is an artist and designed her own card but it's ok - you don't have to!

**In September 2010 the research that the Trust co-funded with money raised by the 2001 Odyssey was finally published, to nationwide media acclaim; Professor Jill Belch and Jane Colby, the Trust's Executive Director, were much in demand for interviews**



## Summary of Media Coverage

### National

BBC Breakfast; BBC News 24; The Today Programme; BBC Radio 4; BBC Radio 5 Live; BBC World Service; BBC News website; Daily Mail; Daily Telegraph.

### Scotland (where the research was carried out)

BBC Reporting Scotland throughout the day, including bulletins and lunchtime and evening television programmes. BBC Health Correspondent Eleanor Bradford's report featured Jozef Mackie, now our Young Spokesman, and his mother Donna. BBC Radio Scotland throughout the day, including live interviews with Professor Belch and Jane Colby, interview clips from Jozef and Donna Mackie. Also STV; Scottish Daily Record; The Scotsman; The Times; The Telegraph.

### England

BBC Radio Shropshire; BBC Radio Ulster; BBC Radio Newcastle; BBC Radio Swindon; BBC Radio Gloucestershire; BBC Radio Tees; BBC Radio Coventry; BBC Radio Oxford; BBC Radio Lincolnshire; BBC Radio Hereford and Worcester; BBC Radio Kent; BBC Radio Leeds; BBC Radio Cumbria; BBC Radio Coventry and Warwickshire; BBC Radio Bristol; BBC Radio Humberside; BBC Radio Leicester.

### Northern Ireland

UTV (Ulster Television); BBC Radio Foyle.

### Wales

BBC Radio Wales; Radio Tay.

### Also

Press Association; Trans World Radio; Shine Radio (Birmingham City University); Yahoo; Boots; NHS; Nursing Times; various health websites.

*To give you a flavour, here are transcripts of three BBC radio interviews: the BBC World Service, BBC Wales and BBC Scotland, where the research was carried out. As you see, the essential messages have been repeated and spread worldwide.*

### BBC World Service 07 September 2010, 12:45pm

*Scientists in Scotland have found new evidence that ME, or Chronic Fatigue Syndrome could be caused by a virus. They studied children affected and found abnormalities in their blood which they say points to an infection. It's reckoned that millions of people, mainly in the developed world, have ME; many of them are children. Jill Belch, who's Professor of Vascular Medicine at Dundee University, led the research.*



*Jill Belch  
Professor of Vascular Medicine  
Head of Centre of Cardiovascular & Lung Biology  
Ninewells Hospital & Medical School*

There's two important things that we've found, and the first is that there's an abnormal level of an inflammatory chemical in the blood, and this is matched by abnormal white blood cell behaviour, and that's important because finding an abnormality is half way to finding a treatment. But the second thing that I think makes these findings important

# Our Biomedical Research

## media coverage upon publication

is that it is a physical abnormality, and there has been some question in some people's minds as to whether this disease might actually be a disease of the mind, and I think finding a physical abnormality reassures us that this is a genuine physical illness.

*Indeed, some Doctors have been reluctant to diagnose ME, in the belief that it is a disease of the mind. Jane Colby was a Head Teacher until she was struck down by ME; she's now Executive Director of The Young ME Sufferers Trust here in the UK. First, her reaction to these new findings.*



Jane Colby  
Executive Director  
The Young ME Sufferers Trust

I welcome it, and frankly it's exactly what I would have expected, because the important thing is, it's not just evidence of infection in children with ME, but persistent infection. So they're fighting something, and they're fighting it on an ongoing basis, which means there's an explanation for why they are so ill for so long.

*And how do they get this infection?*

Well, until you know exactly which virus is causing it, you won't know the exact method of transmission, but generally speaking these viruses are around in the community; what happens is, not everybody has a bad

response to them - some people will throw them off, but some people will not, and then you can get the complications which turn into ME.

*Does it also offer further evidence that ME cannot be a psychological illness?*

Well I would say so; I mean nobody is saying that you can't get very upset and fed up and even depressed sometimes from being ill for so long, but that's completely nothing to do with the fact that you have got a viral infection.

*So what are the full range of symptoms then?*

Basically, if you do too much, you will either relapse or be a lot worse, and have to recover from it over a period of time. You have loss of concentration, your brain may not work properly and in my own case I have to say my brain was so badly affected I actually forgot how to walk, I forgot half my vocabulary, and I was so sick that I could only just feed myself.

*Did it come on very suddenly, like an infection, in your case?*

Oh definitely. I was a Head Teacher; I had terrible pains in my back and thought I was getting 'flu, and it wasn't 'flu; it turned out to be a virus related to Polio. It put me in bed for years, and then in a wheelchair.

*How much scepticism did you face, when you went to see your Doctor about your symptoms?*

I was actually diagnosed with ME; I was very fortunate because my GP was on the ball, referred me to the best Microbiologist in the country at the time, who knew all about it, and so that was all very quick. What was not good was the advice I got afterwards. I made myself far, far

worse as a result of which the whole thing went chronic for years.

*Is it the case though that some people who go to their Doctors, suffering from the sort of symptoms you've outlined, aren't believed, and Doctors refuse to diagnose ME? Has that been happening?*

Yes, it is very often. Especially with children, they're afraid to say ME or Chronic Fatigue Syndrome or whatever they choose to call it. They're afraid to say it, because they think it's a self-fulfilling prophecy and you will believe that you're going to be ill for years, and therefore you will.

*What do young ME sufferers need then?*

In the absence of something that will zap this virus, they need to have time to recover. Mostly that means education at home, and not being forced to do too much.

*Can the symptoms be different from person to person? Can they be very severe in one case and mild in another?*

Well, like any other illness, yes you're going to get severe cases. The important thing to do is not to let a milder case turn into a severe case, and if you manage it wrongly that's what it will do.

*Do you believe there will be a cure for ME one day?*

Yes I do, but that's with the will to invest in identifying the virus, producing an anti-viral, and possibly even a vaccine; there's no reason why it shouldn't be possible.

*Jane Colby. You're listening to News Hour from the BBC World Service, with James Menendez*

*There's more evidence that ME, or Chronic Fatigue Syndrome, could be caused by a virus.*

*Scientists in Scotland have studied children affected and have found abnormalities in some blood cells. It's reckoned that 150,000 people in the UK have ME; 15,000 of them are children. Jane Colby is with us now; Chief Executive of The Young ME Sufferers Trust. Very good morning to you.*

Hello.

*This research that it could be a virus: does it come as a surprise to you?*

No, not at all; it's exactly what I would have expected to find. I also would say that it's not just evidence of infection; it's evidence of persistent infection, in other words something ongoing that the children are fighting on a long-term basis, and they have faced so much disbelief, and schools trying to force them back into school, not being able to believe why they are ill for so long; clearly this gives us a reason.

*Why has it taken so long to find this out?*

Well there is a problem about scientific funding. There really is; I would say there has been a plethora of psychological research into psychological treatment, and an absolute dearth of biomedical research studying what is actually going on in the body, and science should be about finding out the truth.

*You mentioned the controversy and preconceptions about ME. Now this, if indeed everybody does rally round this research, should transform the perception of ME now?*

I would hope so. Really the problem has been these psychological treatments, with some kind of

impression that that is going to cure people. You cannot get rid of a virus with psychological treatment. Children are isolated simply because they are too ill to get out and about, and it can be very long-term. It's not all in the mind, and there is clearly a scientific grounding for the severity of the illness, and now of course the Holy Grail is trying to find out what that virus is, and treat it.

*And that is indeed the Holy Grail. Are you confident that it will be pursued vigorously?*

Well I think again that we are down to a problem with funding. Dr Rosemary Leonard, the BBC Doctor this morning actually cautioned that because an ME charity had co-funded this study, the results should be interpreted with some caution. But who else is going to fund this sort of study? I mean generally the research has been into psychological treatments, funded by grants to doctors who have specialised in providing those treatments themselves, so you could equally well caution against that.

We do have a problem with funding, and I really think grants must now be made to study the proper scientific basis for this illness.

*Thank you very much Jane Colby, Chief Executive for The Young ME Sufferers Trust.*

### **Biochemical and Vascular Aspects of Pediatric Chronic Fatigue Syndrome**

*'We showed for the first time, to our knowledge, that oxidative stress [...] and increased WBC apoptosis occur in children with ME'*

*'The data are also consistent with a reactivating or persistent viral infection'*

*Arch Pediatr Adolesc Med 2010;164(9):817-823*

*Scientists at Ninewells Hospital in Dundee have found further evidence that ME or Chronic Fatigue Syndrome could be caused by a virus. They found abnormalities in patients' white blood cells suggesting they'd been fighting off infection. ME has been difficult to diagnose in the past and has often been treated with scepticism, even by the medical profession.*

*Jane Colby is Executive Director of the charity The Young ME Sufferers Trust and she joins us now. Hello Jane.*

Hello.

*It's quite common, isn't it, for people to present with symptoms of ME and not to be believed, quite simply?*

I should think it's the norm, to be perfectly honest. What I think is so brilliant about this research is that finally we've got evidence that this isn't just an infection: it's a persistent infection, which means that there's an explanation for why children in particular are ill for so long, and can't get to school and are often suspected of just being school-phobic.

*The problem is, until you actually have something you can test for, it's very difficult, isn't it, to prove whether somebody has that, or something else even?*

Of course it is, and people have been very reluctant in the medical establishment to accept that there is a viral origin. Now that we know there almost certainly is then they need to be looking for what virus, and then you can treat it, can't you?

*Do you hope though, that even in the meantime, you'll be able to get a test that says ok, you do have ME; we know what you've got; we may not be able to treat it effectively, but at least we can diagnose something?*



Well it is the next step, isn't it. Clearly, before you have a treatment, you've got to be able to know what is the organism that is doing it, and we should be looking for that.

*Why do you think there's so much scepticism over it? It's become a disease that even doctors are very reluctant to put down on a medical notice; why do you think that is?*

Well, there are several reasons. One is simply the fact that seeing is believing; you only see children with ME, or indeed adults with ME, when they're well enough to get out and about. You never see them when they're stuck at home in bed, in pain, perhaps even having to be fed by tube because they can no longer swallow. People don't see these terrible sides of it, and of course I do, and I've experienced it myself too, so I know it's not made up.

*What symptoms did you have, and how have you got over it?*

I was a Head Teacher, and I was waiting for a Government Minister to visit the school, and I had terrible pains in my back and thought I was getting 'flu. It wasn't 'flu - it turned out to be a virus related to Polio. It put me in bed for years and then in a wheelchair, and I was in terrible pain; I forgot how to walk, my brain forgot half my vocabulary, it was absolutely horrendous, and the only way I actually survived was somebody else cooking my food, so that I could eat what they gave me, because I couldn't have cooked anything.

*And was that a classic case of ME?*

It was a very severe case; they're not all as severe as that, thank goodness, and the most important thing is to prevent the cases that children get, and adults get, but children in particular, you must

prevent them getting worse so they don't get to that stage.

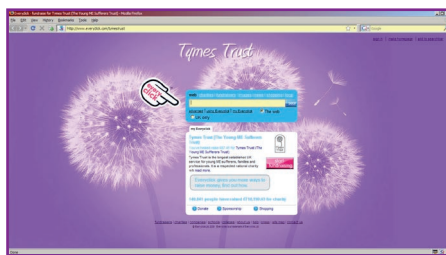
*How do you do that? Is there any way at the moment?*

Oh definitely. Their bodies are fighting an infection - we now know that - and you need to let the body recover. Now if you force them into school, force them to do all sorts of activities that they are not fit to do, you make them relapse, and relapse, and relapse, and they can get worse and worse and worse, so they very often need education at home, for quite considerable periods.

*So do you think then that the attitude of people, 'Oh just go to school; it's just a cold; you'll get over it', which is quite common these days, is just completely wrong?*

It is completely wrong. Absolutely right - this is not a matter of thinking your way out of it. No amount of psychological treatment can get rid of a virus, now can it?

*Jane, thank you very much for speaking to us. That's Jane Colby, who is Executive Director of The Young ME Sufferers Trust.*



[www.everyclick.com/tymestrust](http://www.everyclick.com/tymestrust)

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

## Quality of life 'profoundly impaired'



When our Dundee study into blood abnormalities was carried out, other data was also collected from the same children and controls, for

this 'quality of life' study. Again, this was funded by The Young ME Sufferers Trust with ME Research UK. The study showed that the quality of life of children with CFS/ME was not only significantly impaired compared with their healthy counterparts, but also when compared with children affected by other chronic illness (type 1 diabetes mellitus and asthma).

### Physical and Functional Impact of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis in Childhood

Key findings with educational implications:

**Only 1 child out of 25 was able to attend school full-time (4%)**

**12 children were attending school part-time (48%)**

**8 children received home tuition only (32%).**

*'These results are in accord with similar findings for adults, indicating that [...] physical symptoms can be at least as disabling as those of multiple sclerosis and other chronic conditions.'*

*'Conclusion: The quality of life of children with CFS/ME was profoundly reduced, compared with that of their healthy counterparts.'*

*Pediatrics 2010; 125:e1324-e1330*

# National Institute for Clinical Excellence

proposes not to review its 2007 guidance on CFS/ME; we disagree

We have sent the following to NICE as part of their stakeholder consultation process:

## National Institute for Health and Clinical Excellence Review of Clinical Guideline (CG53) on CFS/ME

### Stakeholder Comments

**Do you agree with the proposed review decision?**

No

**If no, please add any reasons / comments below**

There are two new research papers that provide new evidence which we feel have important implications for the existing NICE treatment recommendations.

The first is *Biomedical and Vascular Aspects of Pediatric Chronic Fatigue Syndrome* by Gwen Kennedy et al, Arch Pediatr Adolesc Med. 2010;164(9):817-823). This showed that 'biomedical anomalies seen in adults with CFS/ME - increased oxidative stress and increased white blood cell apoptosis - can also be observed in children with clinically diagnosed CFS/ME compared with matched controls'.

The conclusion of the research team was that these children showed evidence of persistent viral infection. Although the remit of NICE does not include aetiology, if aetiological discoveries have relevance for treatment we believe that such discoveries must be taken account of by NICE.

This discovery could have great relevance for graded exercise therapy and could well explain why patients commonly report being made worse by exercise during their long recovery process. There is plenty of evidence from patients to show that those who are not treated with graded exercise make good recoveries over time, as in any other viral illness for which there is as yet no antiviral treatment.

The second paper is *Close analysis of a large published cohort trial into fatigue syndromes and mood disorders that occur after documented viral infection* by DP Sampson, Bulletin of the IACFS/ME, which reanalysed data used by Professor PD White in his Lancet study upon which much of the deconditioning theory of ME/CFS appears to have been based.

Sampson argues that Professor White's conclusions are not supported by the evidence in his study. If this is indeed the case, then the theory upon which graded exercise treatment is based may be flawed, which could have profound implications for NICE treatment recommendations.

**If there are any areas excluded from the original scope that you feel need to be addressed in any update decision, please write these in the box below**

In the Dept of Health Report 2002, there were some very helpful comments about the fact that children with ME/CFS may require education in the home for quite some time. Doctors need to be informed that there are 21st century educational options eg interactive virtual education, which have proven their worth in terms of the child's recovery from ME/CFS, and which are commonly provided by Local Education Authorities (LEAs) WHERE THIS HAS BEEN REQUESTED/RECOMMENDED.

We are not suggesting that NICE should recommend one sort of education over another, because that is clearly a matter for educationists and is outside the remit of NICE. However, it is not sufficient simply

to advise doctors to liaise with schools and LEAs, as doctors are commonly unaware that there are effective options other than school. It is important to bring alternative forms of education which are energy-efficient to the attention of doctors managing cases of ME/CFS.

GPs and paediatricians need to know that there are other choices available to help their young patients. Such options have a track record of producing good educational qualifications for the children, and evidence from Local Education Authorities shows that the children are often able to return to school as their health improves.

**If there are any equality issues relevant to the guideline that you do not feel have been adequately addressed please write these in the box below**

The issue of the rights of children with disabilities is not sufficiently addressed. At the moment they commonly suffer discrimination.

It should be made clear that children with ME/CFS may require wheelchair assistance, for example. In school they may need assistance with carrying bags, facilities to study on the ground floor, or to use lifts.

Doctors often refuse to endorse requests for a wheelchair when they believe that ME/CFS is a psychological condition or believe that there are psychological issues which perpetuate the illness. They say things like 'once in a wheelchair never out', or simply state that having a wheelchair will prolong the illness. There is no evidence for this, and anecdotal evidence is overwhelmingly to the contrary.

# Join our Exams Letter Campaign

ask us if you would like a signed copy for your school or college

## *To the Chair of the Governing Body : Students with ME taking exams*



I am writing to you as a former Headteacher who became severely disabled with ME due to a viral infection related to polio myelitis. ME is a serious neurological disease (World Health Organisation Classification ICD10 G93.3).

I assisted the government with the 2002 Department of Health Report on CFS/ME and this year our charity received the Queen's Award for Voluntary Service, the MBE for volunteer groups, for pursuing the educational rights of children with ME and advancing their care.

Children with ME who cannot study in school face serious educational disadvantage. The Queen's cousin, Lady Elizabeth Anson, gave the following speech for an event we held on ME Awareness Day at the House of Lords:

*As a patron of the Young ME Sufferers Trust it is my honour to present the 2010 Learning Commitment Awards. These annual awards are designed in partnership with the Nisai Virtual Academy. They recognise the achievements of young people who, for reasons beyond their control, cannot attend school or college. Some of the recipients of these awards have ME while others face different barriers to education.*

*Your achievements are even more extraordinary when we consider the difficult circumstances and barriers that have stood in your way. These awards will provide other young people with the hope and confidence to succeed, and your stories will highlight the problems faced by young people out of school.*

*As an ME sufferer myself (luckily this started after my school years) I know how hard it is to concentrate; to read and to absorb what one has just read, let alone the energy to open a book. It is therefore even more commendable and praiseworthy that you have achieved such high standards.*

These sick students have achieved remarkable results. But we have discovered that examinations centres - schools and colleges - are increasingly unwilling to host their examinations after they have studied so long for qualifications, despite their illness.

Our Young Advocate, Shannen Dabson, a teenager disabled with ME who recently managed to address the Royal Society of Medicine despite her condition, told us how heartbreaking it is to be turned away by school after school after studying all year.

Shannen's mother telephoned 30 schools and colleges. Only one had a legitimate reason for not hosting her exam; it was a listed building that couldn't accommodate a wheelchair. She writes:

*It was so disheartening to hear rejection after rejection. Panic began to set in that Shannen may have completed all that work for nothing. Eventually we found two, one in Holborn and the other in South Kensington that was slightly cheaper.*

Can you imagine your students having to travel all that way to central London, early in the morning, and then trying to do their best to get a good grade when they are exhausted at the start?

There really is only one way to describe this situation - terribly unfair. Life has already dealt these students a severe blow to their health; surely we should be doing our best to support them when they try so hard despite their difficulties?

Local Education Authorities have a duty to provide access to examinations centres but it just isn't happening. And, as you know, schools now have a duty to promote community cohesion and to increase the breadth and depth of community engagement.

The physical and emotional well-being of children is also a vital area that must now be addressed.

In view of all these considerations I am asking you to consider becoming a host school for any external students in your area studying with the Nisai Virtual Academy, with whom we work closely and who provide courses for Local Education Authorities. You may only receive occasional requests, but for each student, it will be their future life chances that are at stake.

We will send your school a Young Hearts Certificate to display. Young Hearts Day (November 29) was inaugurated for us by the former special envoy to the Archbishop of Canterbury, our patron Terry Waite CBE, to remember children with ME everywhere. It is on their behalf that I respectfully make this request.

Thank you.

Jane Colby FRSA  
Former Headteacher  
Executive Director, The Young ME Sufferers Trust



# SEB'S MANOR

I hope you have a fantastic Christmas full to the brim of joy, happiness and peace! Love Chloe



## Sebastian Says

Holidays - yay! I'm just so excited! I got an email from Boris Cox:

*Please can i look after sebastian and the tymes trust bear at xmas? love Boris Cox age 6 years*

Everyone at the Trust agreed that I could go, even though it's going to be difficult for them to manage without me. So I am writing my column in a rush because I'm off to visit Boris IMMEDIATELY and I haven't checked that I've got a new padded bag to travel in. I'm looking forward to having some great

holiday photos to share with you all in *Vision*!

(Of course, the new Tymes Trust Christmas Bear is coming too. He can't type so he's asked me to tell you that. He hasn't even got a name yet. I expect Boris and his family will give him one, as it's rather awkward for me to keep saying *Oi, you with the Christmas hat on, or Oi, you with the present in your paws* - and it's not my usual polite style of address either.)

Boris is very kind, you know. He would also have liked to look after the bear on the tymes trust business card with bandages on his head and arms. You know the card he means?

It's got a hidden magnet in it, and you should all have received one in your Welcome Pack to stick on your microwave or your fridge, so you always have our number handy. (If you didn't get one, let me know and I'll send you one.)

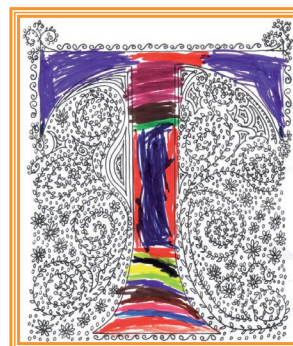
Anyway, Anita wrote to tell Boris the bear on the card's our Virtual Bear - he lives in our computer. And I'll let you into another secret ... he only dressed up in the bandages for the photo - he's OK really, so you needn't worry about him Boris. He says:

*Hi Boris, I hope the Christmas Bear has a great time with you, and I really hope he comes back with a name, because I can't just keep saying OI, YOU WITH THE YELLOW FUR!*



Well said Chloe! I couldn't have bet it putter myself ☺

*The Animals of America*  
By Chloe Halstead  
Tymes Trust Young Artist  
(Did you know she and Kathryn, our Young Artist Overseas, are emailing each other now? They're email buddies.)



## Seb's Clever Colouring

All this Precision Penmanship came from you of course! (I'm quite brilliant at art myself actually - the next time you see a masterpiece signed with eight footprints, you'll know who did it). I am most proud to present the work of Boris Cox (this page),



On my page today I've got some great colourings. As you know, I'm in charge of the prizes and I made sure that Anita sent some of our magic pens to Reeve and Philippa. They change colour when you use the white pen over them. She sent some to Boris too - what a lot of parcels the postman has brought him recently!

Why don't you all join in my Snowman Colouring Comp (or send me some other artwork) and you can have some magic pens too ... or something else if we've already sent you them!

PS If you're reading this after Christmas, you can email me and ask what I did with Boris.



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



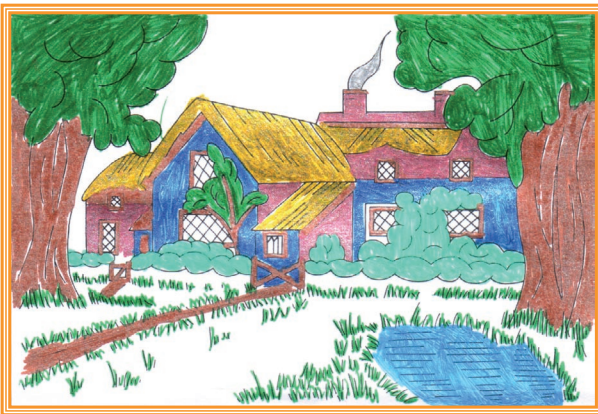
## Seb's Comp

### Colour the snowman

Now don't all cheat!

I know snowmen are white but I do expect a little creativity here ... maybe a jolly scarf, or some snowflakes ... to get some great magic pens from Simon Selkin, our Resident Santa. I bet Simon didn't know we still have some left!

As always, you don't have to cut up your *Vision*. You can send us a coloured photocopy or, like Chloe, you could scan your picture in - just let us know it's ready and we'll tell you where to email it. Have fun!



Reeve Perks (above and right) and Philippa Neville (below and right). Well done!



# Young Officers

## of The Young ME Sufferers Trust

We have appointed two Tymes Trust Young Photographers: Jen Flynn and Sarah Coulbert. They both enjoy photographing nature and will be taking pictures for the Trust.

### Other Tymes Trust Young Officers

Shannen Dabson, Young Advocate

Chloe Halstead, Young Artist

Kathryn, Young Artist Overseas

Frances Goodchild, Young Campaigner

Jozef Mackie, Young Spokesman

Chloe scanned and emailed us her latest sketch, featuring the animals in North America. You can find it in Seb's Manor.

Would you like to be one of our Young Officers? Think about the thing you do best and let us know. Could you be our Young Poet perhaps? We haven't got one at the moment...

I just received the latest miniVision magazine and Things 4 u 2 Do and I noticed your Young Officers piece and would love to help/be a part of it.

I like to take photographs, it has been the only hobby I've maintained throughout my struggle with ME.

Over the years I feel like I've tried every available treatment but

each only seem to offer a short period of relief from symptoms. The thing that continues to help is the knowledge of the support and hard work from people like you.

I'm lucky enough to be feeling a little brighter at the moment, and so I'd love to do something to help those who aren't having such a fortunate time.

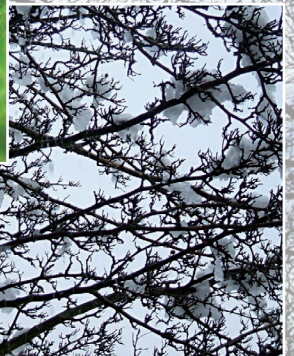
Thanks, Jen



Following the article in miniVision I would like to volunteer use of my photographs by Tymes Trust for Vision. I have several cameras, my DSLR is a Canon 1000D, but I also have a compact digital and two older SLR cameras.

I enjoy taking pictures of local parks and flowers as well as anything that catches my eye indoors. I have to try and balance my camera on the tray of my electric wheelchair, but I am looking at finding an (affordable!) camera stabiliser/holder that can clamp onto my wheelchair frame because I have unconscious movements.

Sarah

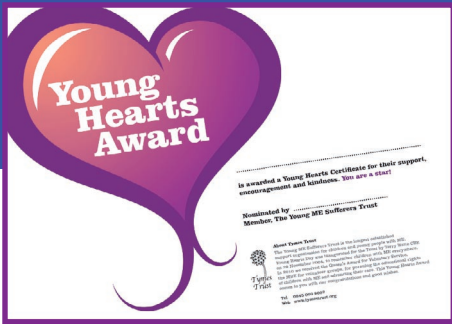




JEN FLYNN

SARAH COULBERT





# Launching our Young Hearts Award!

Has someone in your family given you special support

tutor or neighbour. Anyone who has really deserved this recognition.

Email us on the Contact Us form at [www.tymestrust.org](http://www.tymestrust.org) and we'll tell you how to get your free Award certificate.

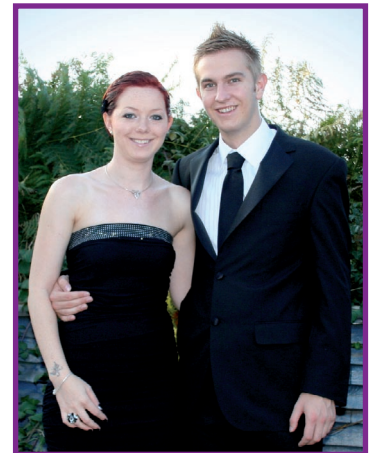
On page 7 you can read about the first recipients of our Young Hearts Award.

and help? You can nominate them for a Young Hearts Award. Send us their name, and tell us how they have helped you. Or you could nominate your GP, or a home

## Young Hearts Award Designer

Russell Meakin

I had ME in my early teens for a few years. I'm happy to say that I'm now clear and can enjoy my life again. Now I'd like to help support the charity which supported me. I'm a fully trained graphic and web designer (I self taught whilst suffering from ME) and would like to offer my services.

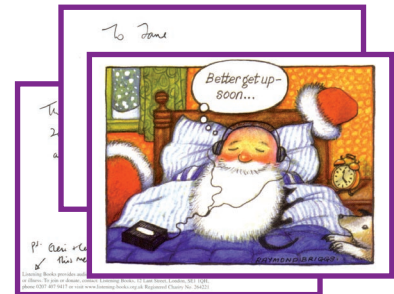


## Listening Books

Audio books can either be streamed online via [www.listening-books.org.uk](http://www.listening-books.org.uk) or sent in the post on CD in MP3 format.

Listening Books have kindly granted some free memberships to our members. Just send to us for an application form.

'Eleri and Cerith have really benefited from this membership.' Card art by Raymond Briggs for Listening Books.



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## By Royal Invitation



On 22 July 2010, representatives of the Trust attended the Queen's Garden Party at Buckingham Palace. It was a glorious summer day. We were invited because the Trust has been given the Queen's Award for Voluntary Service : the MBE for volunteer groups. The announcement appeared in the London Gazette on the first of June - our anniversary!



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

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