

22 July 2006

RELEASE FROM THE BOX - ELIZABETH COLLEY

Jane Bryant writes:

On 27 April 2006, One Click published [The Bravery of Elizabeth Colley](#). This is the story of a young woman previously diagnosed with ME/CFS who has now tested positive for Borreliosis/Lyme Disease. Three months later, One Click now publishes an update on Elizabeth Colley and the treatment that she is receiving that has assisted her so much.

Elizabeth has been suffering under the ME/CFS wastepaper basket diagnosis syndrome label for nine years, since the age of eight. She is now seventeen. Similar to so many children labelled with this illness, Elizabeth's childhood has been ruined and traduced. She has suffered horribly. This is precisely what has happened to my son, suffering terribly under the ME/CFS label since the age of ten and now too diagnosed with Borreliosis with treatment being given.

To her absolute credit and during those dark years, Elizabeth's Mum, Jane Colley, decided to help others and offered her services as a volunteer on the TYMES Trust (The Young ME Sufferers Trust) charity helpline for ME/CFS diagnosed children and their parents. As you will read and after many years, Colley then took her courage in both hands and thought out of the box with stunning results.

Jane Colley writes: "For years we heeded the advice of the ME charities to rest and let her body heal itself." Me too. It will be one of the greatest regrets of my life that I also listened to this dogma that invariably fails to enable the patient to resume a full and productive life. The ME/CFS charities are so often part of the problem and not the solution. Charles Shepherd, Medical Adviser and Trustee of the failing Myalgic 'Encephalopathy' Association (MEA) charity even goes so far as to state in public that all in-depth tests and investigations for ME/CFS labelled patients should be denied, whilst simultaneously burying the file on the links between ME/CFS and Borreliosis provided to him by one of his very own Co-Trustees in 1999. With so many suffering for so long, this is of course an obscenity.

When it has been pointed out with the evidence published that the Emperor so often definitively has no clothes on in relation to these ME/CFS charities, the result has been persecution and wrongful arrest. Read [Freedom Of Information: Police Harassment In The Internet Era](#). Jane Colby of the TYMES Trust charity et al have a great deal to answer for.

And now please read the glad tidings. Read about Elizabeth. One Click takes great pleasure in publishing Case Histories like these. It makes all the work done by our pressure group month after month and year after year worthwhile.

Jane Bryant
The One Click Group

RELEASE FROM THE BOX - ELIZABETH COLLEY

Jane Colley writes:

At the beginning of this year Elizabeth celebrated her seventeenth birthday. She had decided that she would like to have a day out in London but was too ill to leave the house. Things were not going well. Just before Christmas she had given up her struggle to continue attending school. She was very unwell and after nine years of ill health was continuing to deteriorate.

I was at my wits end. I knew that there was something seriously wrong. By chance I was put in touch with someone who is well informed on ill defined illnesses such as ME. I was told Elizabeth would never get better unless I got some help for her. An internationally renowned environmental health specialist doctor was recommended to me.

Elizabeth was offered a raft of tests and immediately decided she wanted to be tested for everything. They took 26 phials of blood, as well as urine and stool samples. Over the next few weeks the results came back. Many of her tests were carried out abroad and just about every test came back with abnormalities.

Borrelia burgdorferi was detected in separate tests at different labs, together with very high levels of Epstein Barr, very low ADP to ATP reconversion, serious problems with moulds, lead poisoning and multiple food allergies.

Elizabeth says she feels that she spent nine years inside a very claustrophobic box, surrounded by packaging, with thick layers of card pushing down on her. Everything was firmly stuck down with red and white tape marked "Fragile".

Like so many parents of children who are diagnosed with ME, I very soon decided that my top priority had to be to keep her safe and at all costs out of the hands of the psychiatrists. Because we truly wanted her to get better and resume school life when her health improved most of our energy went into ensuring that she always kept up with her academic work. Her attendance record was appalling. However, she never gave up and in 2005 sat her GCSE's, mostly at home in bed. She was unwell in fifteen of the exams but

still achieved straight A stars and A's.

The TYMES Trust had provided us with invaluable support with many of the problems we had encountered along the way. I had contacted their helpline on many occasions and received some excellent help. I was asked if I would like to join the helpline and was glad to do this as I wanted to put something back and try to help others who were in a similar situation.

I spoke to some lovely people. The story was always the same, but what really began to hit me was just how many of these children were not getting better. Increasingly, I started to think outside the box, read more and more widely and started to question the wisdom of how I had tackled her illness. For years we heeded the advice of the ME charities to rest and let her body heal itself. I kept going back to Dr Byron Hyde's "The Complexities of Diagnosis". Elizabeth was getting progressively worse. I read a great deal about chronic ME, but was not prepared to accept that this had to be her future.

We are six months down the road. Elizabeth is well and truly out of that box. She is receiving treatment on a number levels. She protects herself from food allergies with a vaccine, takes large amounts of supplements, and is part way through a protocol of aggressive antibiotic treatment. She has been very brave, some days have been diabolical, but throughout she has been steadfastly determined and stuck to the regime.

Last weekend I picked her up from the station, she had just spent four days in London. She looked wonderful. Beautiful, shining blue eyes, a wonderful complexion, smiling from one side of her face to the other. The weight that piles on when she is most ill has gone. She is very proud of her slender waist and exceptionally flat stomach. She no longer looks like a ghost, sleeps normally, and her hands and feet are no longer cold. The changes are amazing. People comment to me that she looks totally different. As she walks down the street radiating happiness people turn to look at her.

After so many years I have got my daughter back. Things are still difficult and there are many challenging days. After a break of four months she has started to study again. In September she starts at a language college, and next summer will be off to New Zealand for her gap year. On her way back she is going to the Olympic Games in Beijing and on her return will read French at university. She is looking forward to everything with such relish.

Elizabeth is investing everything into improving her health and takes things very steadily. Her improved state of wellbeing means everything to her. Tomorrow she is having a session with a personal trainer to start to get fit again and she regularly does detox baths and has just started to use a portable sauna. She is determined to fight the Borreliosis.

I had to stop helping the TYMES Trust. I find it hard to come to terms with the fact that the advice I heeded for so many years contributed to the

seriousness of the bacterial infection she has had for so long. For over nine years I naively let her health deteriorate and allowed the spirochetes to make themselves very much at home. I should have followed my instincts and thought outside that box much sooner.

Jane Colley
22 July 2006

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FOR FURTHER INFORMATION:

[Is CFS/ME A Bacterial Illness? Dr. Andrew Wright](#)

[The Impact of ME/CFS Misdiagnosis](#)

[The Story of My Partner's Health](#)

[Lyme disease: ancient engine of an unrecognised borreliosis pandemic](#)

[Video-microscopy and pictures of Borrelia burgdorferi and other spirochete like structures links collection](#)

[The NHS - BADA Letter to the ME/CFS Community](#)

[NHS Primary Care Question Answering Service - Lyme Disease](#)

[Borreliosis/Lyme & M.E. In The United Kingdom](#)

[Diagnosing Lyme Disease in People with ME/CFS and/or FMS Symptoms](#)

[ME/CFS/FM Support Group USA - Borreliosis News](#)

[What is Lyme? Borreliosis?....Information](#)

[Borreliosis - The Jigsaw Hypothesis, Dr. David Owen](#)

[A life cycle for Borrelia spirochetes, Alan B. MacDonald](#)

The above represents just a very small selection of the papers and documents relating to Lyme Disease/Borreliosis. There is much information on this issue around the world. The One Click Group website holds a dedicated Borreliosis section. Click [here](#)

The work of Dr. John Gow shows that the gene expression between Lyme Disease/Borreliosis and ME/CFS is identical. It is also the case, however, that the patient suffering from previously untreated Lyme Disease/Borreliosis is often subject to a number of co-infections such as Mycoplasma, Babesia,

Bartonella, Ehrlichiosis et al.

An excellent charity that helps Lyme Disease/Borreliosis patients in the UK is [BADA](#).

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