

Charitable Registration No.: 0810341-11

The Nightingale Research Foundation

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December 12, 2017

Loné and I, the Nightingale Staff, Lenka and Donna and our board want to wish you and your family a wonderful Christmas and a healthy and prosperous New Year.

So, what is New? It all began with a house call in England I made earlier this year to a 12-year old girl, who fell ill with M.E. on Christmas day 2014. She was then only 9. She has remained ill and deserted by her physicians. Her doctors tried to separate her from her family and send her to a psychiatric hospital. **Why?** Because many physicians in the UK, as in Canada believe "M.E. is a psychiatric disease." Look how many M.E. patients are treated by their physicians with anti-psychiatric, anti-depressive, anti-anxiety medications, which not only tend to cause obesity, they slow down mental cognitive abilities even more, but do not help the patient or get them back to work or school. Many of these psychoactive mediations make the patient worse.

So when Amy's mum telephoned me, of course, in part because she was a child, I went to see Amy hoping I could be of help and to find a physician to take care of her. In North America most M.E. patients are treated with benign neglect. Which may sound terrible, but it is better than being committed to a psychiatric hospital, which can occur if you are a child with M.E. in England. Her story is told in the enclosed booklet. You will learn a great deal from her story, since unlike most individuals with M.E., her illness started with a clinically visible enterovirus. So I invite you to read this truly Christmas story.

The Terrible Tale resembles a Charles Dickens-like story, where Scrooge represents the doctors who misdiagnosed this child. Amy lives with her parents, her two lovely sisters, her tail-wagging doggie whose name is Winnie, and when I visited her, her two guinea pigs, Betty and Primrose. Amy is now 12 years old and has been ill and deserted by her medical community for the past three years. The 32-page booklet clearly documents how a classical case of M.E. occurs, how it begins with a known enteroviral infection, which in turn caused several cascading disabilities. Nowhere in the M.E. literature is this cascading illness described as in this child's terrible story. I don't think any M.E. person or M.E. or CFS authority has ever used this cascading term before. It works this way:

- a. Amy falls ill at Christmas with a known enteroviral infection,
- b. Which causes, the terrible initial pain, severe chronic exhaustion & the ongoing M.E. disabilities,
- c. This virus in turn, caused changes in her brain's mechanics and administrative abilities,
- d. These brain changes then cause (a) intellectual, administrative and cognitive dysfunction,
- e. The changes then caused physical dysfunction, in the muscles, and in worse case M.E. causes the:
- f. Autonomic system injury regulating her ability to respond to normal physical activity is injured,

g. Finally, unlike any previous description of M.E. by anyone, this story develops the concept of M.E. as a cascading disease, where one injury leads to another, and another, and another. What is different about Amy's illness is that unlike most enteroviral infections, which tend to be invisible to all but the patient, sometimes written off as "flu" or a "cold", this enteroviral injury was clearly visible.

We are also now hosting **A new Nightingale website**, that can be reached by just clicking **Nightingale.ca**. At the moment the website contents are very limited.

HOW HAVE WE SURVIVED FINANACIALLY? Approximately, 30 years ago, I did a house call to a lady in Hamilton Ontario area with M.E. and was able to help: (a) I obtained a physician for her, (b) I obtained a disability pension for her that had been refused. I never heard from her again. In 2005, she passed away and left a third of her humble estate to Nightingale. She must have been incredibly lonely; she left another third to TV Ontario and a third to US Public Television. Then three years ago, a family in Quebec also left Nightingale some \$6,000 dollars. Nightingale has continued only because of your and their unanticipated kindness.

How can you best help Nightingale and other M.E. Patients?

Nightingale needs your help in Fundraising: You can be our fundraiser. Send a copy of **The Terrible Tale of Amy Brown** to your friends and contacts and perhaps some of them may donate to Nightingale. Nightingale will send a chartable donation receipt for funds received with any donation over twenty dollars. Amy's story not only explains M.E., which so few individuals and physicians understand.

Donations can also be sent by Internet to:

https://www.canadahelps.org/en/charities/the-nightingale-research-foundation/

May I wish you and your family, a very Merry Christmas, and a happy and prosperous New Year and of course, my many thanks for your considerable support over the years.

Byron M. Hole M.D.

Byron M. Hyde MD

Our office manager, Lenka, will be in the office as of January 8th, when public school returns in Ontario.