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The Terrible Tale of Amy Brown



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The Nightingale Research Foundation

Byron M. Hyde, M.D.
121 Iona St. Ottawa, Ontaiio
Canada K1Y 3M1

www.nightingale.ca

office@nightingale.ca

The Terrible Tale of Amy Brown

Unfortunately, the Terrible Tale of Amy Brown is a true story concerning a lovely nine-year-old girl. She could be your sister. She could have been your beloved daughter. Our Amy was nine years old when she first fell ill, and is now thirteen and still disabled. Amy has been virtually abandoned by everyone except her family and friends. How many youths like her exist in England, and in your country, undiagnosed, untreated?

Amy's story will let you understand an all too common, very serious illness, whose name I leave for you to discover. Can you diagnose this illness? Her fifteen physicians, none of whom appear to have taken a good patient history, and none of whom appear to have done a complete examination, missed the diagnosis.

Byron M. Hyde M.D.



Canadian Charitable No.: 0810341-11

The Nightingale Research Foundation

Byron M. Hyde, M.D.
121 Iona St.
Ottawa, Ontario
Canada
K1Y 3M1

www.nightingale.ca

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The Terrible Tale of Amy Brown

A Classical Tale of Myalgic Encephalomyelitis

This story begins with a lovely nine year old schoolgirl who lives with her family in an amazing and sometimes turbulent country called England. It once had one of the best public health systems in the world. It is still a country full of good and kind people and great physicians, but sometimes physicians are too busy and miss important illnesses. This is such a story.

Amy has two younger sisters in school and two older working brothers in their early twenties. The family has a friendly female dog, Winnie, who sometimes piddles on the floor when she is too excited and, of course, the two sleepy guinea pigs whose names are Betty and Primrose. The family lives in a charming and tidy community where they own their own modest and happy home complete with a climbing rose bush beside the front door. Amy is one of those children who loves her family and who is active with her numerous friends. She enjoys her local school. She is an active sports participant. In fact there is little to distinguish Amy and her family from many thousands of happy girls and hard-working families across the United Kingdom. Let us call her **Amy Brown of England** to protect her identity, as long as you remember Amy Brown is not Amy's real name and this is not a fairy tale.

Amy's medical history is of no particular interest to this story either since, other than routine minor colds, she has always been a healthy child. There has been no history of a serious illness. She has received all of her recommended immunizations. Were you to meet Amy and her two younger sisters, I have no doubt you would find them the most charming of children. Theirs is a healthy extended family with no history of any psychiatric disease, no depressive disease or schizophrenic history. In fact the only significant family medical history I was able to uncover

was two or three persons in this hard working extended family with a history of migraines. Amy's family is the kind of bright, hard working English family the nation has been built upon. These are good people. Amy is a great girl, the kind you would want to have as a daughter or sister. But then the wicked witch arrived in the form of an innocuous virus.

Let me also tell you this is both a true story as well as a mystery story.

I don't want you just sitting back there relaxing. I want to invite you to try to unravel this mystery with me, since her doctors did not. In fact, approximately fifteen doctors were to see and reputedly examine Amy, both family physicians and the physicians in the two hospitals where she was taken to. They all missed the obvious diagnosis. Can you unravel the mystery? Try!

There is a basic tenet in classical and modern medicine, which is, a complete medical history and a thorough physical examination should be done to arrive at a correct diagnosis. To my knowledge this principle is taught in every medical school in the world. I hope I am mistaken, but it appears, that not once was Amy thoroughly examined, and that not once was a complete medical history taken by any of the nine principal physicians and the six additional physicians who were superficially involved in Amy's investigation and care. This failure then led to near catastrophic consequences.

Please do not take this story as solely a criticism of English physicians. Many of my patients in Canada tell me they are only allowed to see their physicians from six to eight minutes. They are only permitted to ask one question before they are ushered out the door. It may be there is a worldwide contagion of assembly line medicine. Fortunately, most of the Canadian physicians to whom I refer patients take incredible care in properly listening to and examining patients. I know that similar excellent physicians can still be found in the UK.

But in many ways this is a puzzle so first let me give you a hint. The story is a bit like those Russian wooden Matryoshka or Babushka Russian nesting dolls, one inside the other. As soon as you open one doll, there is another inside, and another...
Matryoshka or Babushka Russian Nesting Dolls



The First Matryoshka Doll

All was well until the Christmas season of December 2014. It was the 23-24th of December and Amy and her family were going to their mother's aunt for Christmas. It was about then when Amy developed a slight headache. Initially, no one took much notice. It wasn't all that significant. But by the next day Amy was getting a bit listless and the headache was getting worse. So she stayed overnight at her aunt's. The next morning her Aunt phoned Amy's mum to tell her Amy now had an elevated temperature. Amy's temperature had shot up to 40C (40 C = 104 Fahrenheit). (normal is 37 C = 98.6 Fahrenheit.) It was assumed at first she had the flu or perhaps the headaches were the beginning of the family's migraine. Everyone was sure it would pass. They kept her in bed and everyone thought it would soon be better with a bit of loving care, just like any bad cold or flu.

But Amy's "flu" didn't get better and, although the temperature went down somewhat, the headaches became increasingly severe and now there was a significant diagnostic rash breaking out on her hands, around and inside her mouth and perhaps elsewhere. So they phoned their family physician for an appointment. He

agreed to see Amy at the beginning of January in his office. When he first saw Amy, he didn't appear particularly concerned. He didn't do much of an examination. After all, it was a cold or flu. In fact this doctor saw Amy on three brief occasions during the next ten days and over this period she was becoming increasingly symptomatic, increasingly ill. Her headaches had now become unbearable. By then, Amy's skin lesions were now breaking out on her hands and wrists, inside her mouth and around her lips. Nobody looked at Amy's feet. The doctor diagnosed herpes and put her on a herpes antiviral medication. Amy was not getting better. The medicine didn't help at all.

The fourth time Amy showed up at the doctors, if it was possible, her symptoms were worse, but now there was a new physician present. Amy was almost comatose. At this point Amy's headaches were so unbearable she must have felt she was going to die. In addition, she now had difficulty passing urine. She was very weak and she had difficulty standing without falling. A doctor might have diagnosed Amy's attacks as a form of syncope. But they didn't. At times, Amy even had difficulties maintaining normal consciousness. Physicians might have then diagnosed encephalitis. But they didn't. She had profound muscle weakness and pain. She had pain in her stomach and chest but the worst was her head pain, and her head often felt like it was exploding. And unlike Winnie her dog, Amy now had difficulty passing water but there was no obvious urinary tract infection. Her doctors might have diagnosed interstitial cystitis which can be seen in some entero-viral infections. But they didn't.

This new physician (and fourth visit to the doctor's) apparently did not know what to do or what was the matter, so he correctly sent the parents and Amy off to a regional hospital.

On the first visit to the regional hospital the doctors diagnosed Amy with a post viral illness and sent her home almost immediately. It doesn't seem that any substantial history was taken. Let me remind the reader, this was the fifth medical visit of a very ill child and no real or significant history or physical examination appears to have been done.

Amy's parents were now frightened and almost immediately her desperate parents took her back to the hospital where this time she was admitted. At sometime here, a blood test was taken for herpes simplex but it came back normal. The rash was obviously not herpes. However, as far as I know, no other diagnosis was made concerning the rash, the fever, or the headaches. If at all possible, Amy became increasingly worse. Nor was her weakness, her terrible headaches or her falls getting any better. The doctors then told the parents that Amy was having seizures. So they ordered an electro-encephalogram and prescribed anticonvulsants.

Electro-encephalograms were done. The parents were told there was no obvious seizure activity yet the doctors still prescribed anti-seizure medications and sent her home. According to the parents, due to the perceived attitude of the physicians, they were beginning to believe the doctors thought Amy was having psychotic episodes and biting herself in the mouth.

If she wasn't before, now Amy was now not only frightened but scared out of her wits and so were her parents. Nothing constructive was being done for their daughter.

The parents were not receiving any practical assistance from the local physicians or the local hospital so on discharge they took Amy to a major hospital center 25 miles away to see a cardiologist. There, Amy was again hospitalized. The rash was still around Amy's lips and inside her mouth and on her hands. No one looked at her feet. The headaches were terrifying and Amy was by now half frightened to death. She was nine years old. Her pain was relentless. She was understandably scared out of her wits and started to scream with the pain.

Another physician examined her mouth, which was sore, and diagnosed the significant swollen mouth lesions as due to Amy biting herself. *However, Amy wasn't biting herself.*

The physicians also ordered a Holter Monitor, (a 24-hour ECG), to monitor Amy's heart. This is a machine which can demonstrate

irregularities if done correctly. The Holter was also found to be normal. Of course it was normal, since Amy was lying down during the entire time. A Holter cardiogram only makes sense if there is (a) a fundamental timing mechanism problem or (b) if the patient has an autonomic dysfunction. To diagnose autonomic problems the patient must be active so the doctors can tell how the heart responds to activity. They didn't have her move, or stand, or even climb stairs or walk with the machine.

All the tests were normal. Of course the tests were normal. If you have a fracture of the ankle, you don't do an X-ray of the head. Do the wrong test and you get the wrong answer. At this point, the doctors appeared to take Amy's case as a definite psychotic manifestation and placed her on both narcotics and antipsychotics. This is a child with no personal or family history of any psychiatric illness.

What would you do if you were Amy's parents? Put yourself in Amy's position. She is nine years old with a headache so bad she thinks her head is going to explode. What would you do?

I have not been privy to any of the many physicians' records, only the mother's and Amy's history. But it appears that none of the now several physicians had made any significant diagnostic or treatment progress. The following is a partial list of what was diagnosed:

List of reputed diagnoses

1. Herpes simplex lesions on and around her mouth, which was incorrect,
2. Seizures, (epilepsy) with a normal EEG, which was incorrect,
3. Normal heart action as seen on Holter, which was incorrect had she been active,
4. Psychotic episode associated with screaming. The screaming was correct but Amy was not psychotic, nor were her parents,

5. One physician noted the mucosal lesions inside her mouth to be due to Amy biting herself. This again was incorrect. This was the classical findings of what ? disease.
6. The hand-lesions were diagnosed by another physician. He diagnosed this as hives. He never looked at the mouth lesions, or the feet for that matter. No one did. This was not hives. Again the lesions were the classical stigmata of what disease?
7. Finally, the doctors diagnosed Chronic Fatigue Syndrome (CFS). This is always an incorrect diagnosis, because there is no disease called CFS. CFS is a syndrome based upon a set of symptoms associated with hundreds of different diseases. Most frequently the term CFS is used by physicians in place of either hysteria or anxiety neurosis. CFS is NOT Myalgic Encephalomyelitis. What is the difference?

Chronic Fatigue Syndrome or CFS is in effect a non-diagnosis. Doctors may tell the patient otherwise but for most physicians CFS is just a pseudonym for hysteria or a new name for a psychotic or anxiety neurosis. It is used since CFS as a term is more acceptable to the parent or child than telling them *your child is crazy*. But usually the doctor thinks one thing and the patient hears another. In reality CFS can be a multitude of very serious missed diagnoses, but that is not what most doctors believe. Most doctors use CFS to mean the patient or their parents are “hysterics.”

What is the correct treatment for CFS? There can be no correct treatment since CFS is (a) not a disease, and (b) represents a group of symptoms common to dozens of different pathologies, each with either a correct specific treatment if any treatment exists. In modern western medicine, a correct treatment is associated with a defined patho-physiology.

CFS is a very dangerous word: In the UK, CFS is an exceedingly dangerous term. Even a parent saying their child may have CFS is enough for some doctors to SECTION the child (*to remove the*

child from the parents care) and place the child in a psychiatric institution, i.e. in protective custody.)

In fact, it appears that the only correct diagnosis given in Amy's case to date was a **post-viral illness**, a diagnosis given in the first hospital. But the next question not asked by any of the doctors should have become, **which virus?** Following the negative herpes and relatively normal blood tests and normal cardiac tests, the quest for the actual virus appears to have been forgotten or was perhaps now unimportant to the slowly accumulating number of physicians. It seems the collective misdiagnosis has now become that of a psychiatric manifestation. For a physician, a psychiatric diagnosis is a great diagnosis since it absolves the physicians from doing any further investigative tests.

Even the difficulty to urinate (urinary retention), the diagnosis that sent Amy to the first hospital, was one additional good clue to the correct diagnosis and, along with the classical rash on her hands and mouth, all appears to have been forgotten.

So dear reader, for the first Matryoshka doll...what is your medical diagnosis? I am sure hundreds of people in the UK will have correctly diagnosed Amy's illness, something her physicians had failed to do.

How many of you will have got the diagnosis that the doctors had missed? But for those of you who have not, let me give you another clue. Any one of the doctors could have just gone online to the national virus reference and read what viral illness was current when Amy fell ill. It also helps to know what viruses cause a **Hand ... and Mouth** rash and what are the possible consequences to such a disease? It is incredible and most unfortunately for Amy, no single physician appears to have had taken the time to do answer that simple question or to understand the consequences of their failure.

But there was a very major diagnostic clue all of the physicians should have noted. The following are pictures of Amy, something which all of the doctors saw when they first saw Amy Brown. Those lesions on and around Amy's red swollen lips also extended into Amy's mouth. They were on her hands. Nobody

remembers if the HFM rash was also on her feet.

So what is your answer to the classical diagnosis, which should have been diagnosed and investigated for complications?



Swollen blistered fingers and hands



Swollen blistered lips and mouth extending into the oral cavity

The answer to the first Matryoshka Doll, to the first diagnosis, is:



!!!Hand Foot and Mouth Disease!!!

The First of the Matryoshka or Babushka Russian Nesting Dolls

A big star if you got the first answer right, the one that approximately ten physicians or more missed. Hand Foot and Mouth Disease!

What didn't Amy's doctors do correctly?

Each of the physicians missed a simple diagnosis. How could even a medical student have missed such a simple diagnosis of Hand Foot and Mouth Disease?

If they didn't know how to make such a diagnosis, all they had to do was to look at the viral database to ascertain what viruses were then current. Not one of the physicians did this search.

They didn't do a spinal puncture (lumbar puncture) to see if Amy had encephalitis or meningitis to explain her near catastrophic headache. With this incredible headache, that would have been an acceptable normal test to do.

Yet not one of the many physicians appears to have ordered appropriate viral studies once they knew they had made the wrong diagnosis. Perhaps they did but I have no information suggesting such a relevant test was performed.

No dermatologist appears to have examined the three HFM stigmata or diagnosed the rash once it was proven not to be herpes simplex.

Not one physician ordered a HMPAO SPECT of Amy's brain. It is perhaps the easiest way a physician can

clearly define an encephalopathy. Modern software would show exactly what areas of the brain had been injured. It wasn't ordered. (*Is it possible England is so antiquated it doesn't have Segami Oasis Neurogram software?*)

Apparently, according to the mother and Amy, the circa ten or more physicians didn't once examine Amy with her clothes off. This non-action would have failed any medical student. In fact, during the first 4 visits to the family doctor, not once was Amy undressed and even the skin of her extremities examined. In the first or second hospital, not one of the doctors examined Amy without clothing to determine the extent of the rash. One doctor did see the rash on the hands and fore arms and described it as hives or an allergic reaction. Later, at least one doctor saw the severe rash in Amy's mouth and suggested she was biting her gums. Incredible. *It is incredible that no physician put the hand foot and mouth rashes together. No physician appears to have examined the whole body.*

It also appears that none of the physicians had done a complete history. Once again a reason to fail any medical student.

You might ask how 10 or more very well trained physicians allowed any of the above to occur. Very easy! By the time a third or fourth physician sees a patient, and certainly when the 10th physician sees a patient for the same illness, physicians often don't take a history and don't do a complete physical. Why? They each assume it was already done. One begins to wonder if there are physicians who haven't seen a child or a woman's body without clothing since they first dissected a cadaver in medical school.

A good history! A good physical! These are essentials to all medical students who wish to graduate, yet one wonders how frequently good histories and physicals are done by physicians once they have received their degree. Did any single physician

actually see the rash for what it was?

Revenge ?

Amy Brown was now home again and it was only then the parents saw the incorrect history and physical the consultants had done in the two hospital centres. They were understandably upset. So, on the 25th of April 2014, approximately four months after Amy first fell ill, Amy's dad called the hospital doctor regarding Amy's report to complain of the poor treatment and incorrect history. Amy's father had reason to be angry, but it appeared the doctor then became even angrier. He wasn't going to take any of this guff. Exactly five days later after the father's phone call, the doctor **retaliated** by issuing a Section 47 on the 30th of April 2014. Retaliated is a harsh word, but I believe there is no other suitable word to describe the doctor's reaction.

What is Section 47?

Section 47: Being sectioned in the UK means the state has the authority to take the child away from the parents and place the child in a psychiatric institution. Section 47 takes away parental rights. This has happened too frequently to misdiagnosed children in the UK. In this case, the sectioning of Amy due to revenge to the father's criticism might even be considered criminal. In America it would have been grounds for a legal action against the physicians and the hospital administration for many millions of dollars.

Not only in England, but in Canada and the United States and perhaps in many different western countries, when the physician doesn't know what is wrong, when the often inappropriate tests come back normal, they too often diagnose PSYCHOSIS. In the UK, when the patient is a child, this child be sectioned. The social services are called and they come and seize the child and take the child or youth away.

From the physician's point of view, in most western countries, there are several advantages to giving a psychotic diagnosis. All

physicians are obliged to give a diagnosis, which is essential in all medical record keeping. The medical licensing boards demand a diagnosis. With a diagnosis comes an arbitrary treatment. If the patient's illness is deemed psychiatric, the physician can then refer them over to a psychiatrist. The psychiatrist assumes that the physicians know what they are doing and have excluded all infectious and anatomical medical conditions. Now the physicians can relax and get back to real patients. Psychiatrists have tens or even hundreds of anti-psychotic medicines to experiment with, even if the patient isn't psychotic. However, in my experience, most smart psychiatrists immediately notice there has been a diagnostic error if there is not a true psychosis and release the patient from psychiatric care. They then call the physician and suggest there is a medical cause for this illness.

So why can a good psychiatrist make the correct inference when the GP or specialist internist can not. Because psychiatrists usually take the time to first listen to the patient and take a correct history.

So our great young girl, Amy of England, has been sectioned and the physicians at the major hospital have phoned the child protection agency to pick up our girl and take her away from the family into a nice psychiatric treatment centre.

Then a small miracle occurred.

The social welfare officer came to the family's house, examined Amy, spoke to her and her parents, and must have decided it was the doctors who were mad and not Amy. So social services did the right thing and left Amy in the loving care of her parents, her sisters, her puppy and the two guinea pigs.

But possibly as a precaution, Amy is sent to a school where there were real psychotic children. On the first day one of the psychotic children at the school attacks the teacher and beats her up, injuring the teacher. Amy's parents immediately withdraw their child from this inappropriate school.

Unfortunately, inappropriate sectioning of a child has another very dramatic effect on all such families in England. The families become rightfully frightened of their children's welfare and tend to avoid all physicians. I assume the doctors are happy since they don't hear from this family any more and they have now totally forgotten the patient.

The Second Matryoshka Doll

The second is an easy Matryoshka Doll to diagnose.

Amy first falls ill with hand foot and mouth disease. The disease becomes chronic and Amy develops:

8. A major cognitive weakness and difficulties reading,
9. Visual changes,
10. The worst headache she has ever experienced,
11. Significant muscle weakness and pain causing difficulty walking, and something else, causing difficulty standing. Have you guessed what that may be?
12. Gastric difficulties,
13. Our dear Amy of England now remains chronically disabled, in pain and terribly exhausted upon even minor intellectual or physical activity.

Anyone who has been there or seen anyone in their family with this collection of findings would immediately know the answer:



The Second Matryoshka Doll

**Amy has encephalitis and a myelitis and specifically
a Myalgic Encephalomyelitis!!!**

Over two years pass and Amy is still ill. Not acutely ill as she was, but still bedridden and largely house bound. So the parents call me in Canada and ask my advice.

Why me?

First: First of all the mother knows I am not going to take her daughter away and place her in a psychiatric care institution. Her daughter is safe.

Second: I am a Canadian physician who was invited to come to London on the 6th of March 2010 to address the combined committee of the House of Parliament and the House of Lords at Westminster, on the diagnosis and investigation of Myalgic Encephalomyelitis. I have been invited to speak in the UK at least fifteen times over the years. I have also been working, almost exclusively with M.E. patients since 1984 and edited and was principal author to a textbook on Myalgic Encephalomyelitis. So I am generally known in the UK.

I will review my talk at Westminster at the end of this article.

A Phone Call from Amy's Mum

On July 6, 2016, I received a phone call from Amy's mum and on the next day I spoke with her and her daughter Amy on SKYPE. You already know the history but this is what I discovered.

1. Just before Christmas 2014 the illness began with mild headaches gradually increasing until the headaches were totally unbearable. This continued in an acute form for several weeks and in a sub-acute form and until the present time,
2. Within two days of the headaches beginning, a significantly high fever occurred that lasted for at least 4-7 days,
3. At approximately the same time, Amy developed a peri-oral skin rash both around the lips and inside her mouth. There were also skin lesions around her hands and forearms (her parents did not remember if there were foot lesions). The doctors diagnosed Herpes Simplex and treated her for this despite the herpes test coming back negative. The treatment had no effect,
4. Later they diagnosed hives, an allergic condition,
5. Amy developed difficulty urinating,
6. Then Amy noticed persisting muscle weakness associated with pain,
7. There was a gastric and chest area pain,
8. Amy was having falls when she got out of bed or tried to go to the washroom,
9. During much of this time she had acute and persisting chronic upper GIT difficulties,
10. Then, as the severe headaches ebbed, the parents noted that Amy's heart rate was significantly elevated even lying in bed and she had chest pain. Understandably,

the parents took Amy to see a cardiologist in the more distant second hospital.

11. They had gone to several physicians, first locally, who had diagnosed herpes. Then they went to a regional hospital where they diagnosed a postviral illness and eventually hospitalized her. The parents then took Amy to a major hospital centre where she was initially diagnosed with seizures. The physicians diagnosed epilepsy despite there being a totally normal EEG. Since the tests were all normal doctors appear to have decided Amy was a hysteric and suffered from a psychotic illness and sectioned her.

Many of the several findings noted above were the typical prodromal signs of paralytic poliomyelitis and more specifically what was once referred to as Missed Polio, usually meaning there was no permanent paralysis and deaths were rare. They are also the frequent symptoms of Myalgic Encephalomyelitis. There are no differences between the signs and symptoms of Missed Polio and M.E. Only time and distance separate the two names.

Both the history and the photographs sounded to me like a typical case of Hand Foot and Mouth disease (HFM). This is, in most cases, a minor illness that appears in children from 1-5 years. In older children and adults the consequence of HFM disease can be much more unsettling as they were with Amy.



The third Matryoshka Doll

To understand the third Matryoshka doll you need to do a bit of homework. It helps if the reader, and the physician know their medicine and understand:

hand foot and mouth disease (HFM disease),

the enteroviral causes of HFM disease and what injuries these viruses can cause when either mild or severe cases arise,

the enteroviral cause of Myalgic Encephalomyelitis and its relationship to both HFM disease and to paralytic poliomyelitis.

There would have been no difficulty diagnosing Amy correctly if she had fallen ill prior to 1954 and not in 2014. In 1954 Amy would have been diagnosed with a mild or a “missed” case of poliomyelitis. She had all the findings to make this diagnosis.

Then in 1955 the Salk polio immunization was introduced and shortly after, poliomyelitis disappeared in most of the western world, but not M.E., which often accompanied paralytic polio epidemics. What has been forgotten is that up to 1955, certainly in major poliomyelitis epidemics, it was noticed there were always a significant number of Myalgic Encephalomyelitis patients mixed in with the paralytic cases. There were several major exceptions. One was the 1934 Los Angeles epidemic. Another was the 1957 Royal Free Hospital epidemic in London. In both of these epidemics, more M.E. cases occurred than paralytic

polio cases. It was during this second London epidemic that the name Myalgic Encephalomyelitis was first used to describe M.E. and the term “*Missed Polio*” tended to disappear from the physician’s lexicon.

What is also now largely forgotten is that the three enteroviruses discovered and named after 1949 as polio 1, 2 and 3 (Brunhilde, Lansing & Leon strains) were not the only enteroviruses causing flaccid paralysis and death. The last major epidemic of paralytic poliomyelitis in the Soviet Union was none of the three so-called polio viruses. It was a similar enterovirus to polio, called Coxsackie. Thousands of people died or were paralyzed. Unfortunately, this Coxsackie virus and the other enteroviruses causing paralysis and M.E. weren’t included in the Salk and later in 1961, the Sabin oral polio immunizations. If it were possible and if the entire enterovirus family had been included in the immunization, I believe there would be no new cases of Myalgic Encephalomyelitis today and no cases of flaccid paralysis and death caused by the other enterovirus infections. Also, Amy would not have fallen ill and become seriously disabled.

Let us review Amy’s disease for you. First, HFM disease in humans is not the same disease with a similar name, Foot and Mouth disease (or Hoof and Mouth Disease), that farmers infrequently see in cattle and cloven hoof livestock in Europe. This does not spread to humans.

I would like the reader to understand that all viral infections have a spectrum or degree of injury. Most viral infections are simply bothersome or give no symptoms yet may cause the patient to become immune from subsequent identical viral infection. The same virus which caused no injury to some people can also cause significant and sometimes chronic illness and at times death. The difference depends upon many factors related both to the virus and the person infected.

Hand Foot and Mouth Disease (HFM) In children tends to be a relatively mild disease, particularly when it occurs in children from age one to five. Yet these HFM viruses are very similar to the

several different paralytic polo-viruses in that they have only about a 5% genomic difference from polio viruses. Like poliomyelitis, most of these infections pass by without serious consequences. Most people do not even fall ill. Like the 3 different enteroviruses which cause polio, Hand Foot and Mouth disease is also caused by several different but similar enteroviruses. Like polio, less than 5% of the several Hand Foot and Mouth viruses go on to cause serious chronic illness. But many enteroviral illnesses tend to vary in their destructiveness with age. In severe cases like our Amy Brown, some patients fall seriously ill with:

1. muscle weakness,
2. encephalopathy,
3. pain syndromes
4. cognitive difficulties,
5. paralysis and sometimes death.
6. in some cases such as with Amy, the area of the brain related to POTS or dysautonomia is injured.

This has been happening regularly, particularly in Southeast Asia, and has spread to North America, Europe and the UK. Thousands of children and adults in Southeast Asia have fallen ill, some have become chronically ill, some have been paralyzed and many died during the past 10 or more years. It has spread to North America and to Europe and England.

Epidemic paralytic poliomyelitis may never have existed until 1881 when it was first reported as occurring among twelve people in an isolated single room school in northern Sweden. Then from 1881 until 1905, when the first major paralytic polio epidemic broke out in Sweden and Norway, few physicians took much notice of polio. Some even called it mass hysteria. It was only after 1905 that paralytic polio became a world threat. The increasing instances of non-polio paralytic virus infections around the world over the past ten years makes me concerned that soon, a new and possibly massive epidemic could soon occur in the west as it has over the past ten years in China and Southeast Asia.

Over recent years I have seen several teachers who have fallen ill due to this virus. Sometimes students tend not to be very ill, so they go to school and can infect their teachers who then fall very ill with what many know as Myalgic Encephalomyelitis. Not all of those injured are associated with significant pain but all of them are, in effect, a missed encephalopathy. In my experience with adults, it has occurred most often amongst students, teachers and health care workers. When HFM occurs in either primary or secondary school children in Canada, in most children it is not a very serious illness so they are sent to school and their teachers sometimes pick up this illness as an encephalomyelitis. In my experience some adults tend not to have skin lesions.

In children and adults with HFM disease, particularly with enterovirus A 71, the illness can be significantly worse. The epidemic and sporadic disease, Myalgic Encephalomyelitis (or M.E.) is one of the more common chronic effects. The urinary and other symptoms that sent Amy off to the first hospital are common findings in both polio and M.E. infections.

The Poliomyelitis and M.E. enteroviruses are similar but have adapted to different loci in the body. **Above the brain-stem and in the brain**, the very similar enteroviruses that cause M.E. injure small blood vessels supplying the cognitive and administrative neurons. However, due to the protective organization of the brain, there are multiple blood supply sources to neurons in the brain, so death from M.E. is rare. It is also possible that the major M.E. pathophysiology is arteriole cuffing and that autoimmune forces then play a significant role around this cuffing causing disease chronicity.

So which of the enteroviruses seriously injured Amy Brown? We know it was an enterovirus because Amy fell ill with HFM disease. But we don't know which enterovirus. HFM disease in humans can be caused by several enteroviruses and the doctors didn't bother to check which one. So the guess is yours. There are probably more than three such enteroviruses causing HFM

disease. The most recent and most common enteroviral (EV) causes of HFM virus and HFM associated M.E. in the UK are probably the following:

Type 1: Hand Foot and Mouth (HFM) Disease due to

Enterovirus 68: One of the several causes of enteroviral HFM disease circulating in the UK in July to December of 2014, the same year Amy first fell ill, was EV 68. This virus, EV 68 (enterovirus 68), not only causes HFM disease, it is also the same virus killing and causing flaccid paralysis and muscle weakness in older children and adults. EV 68 is a disease entity almost identical to polio 1, 2 and 3 that has occurred across North America and Europe during the past few years but was particularly present in 2014, the year Amy first fell ill. To date, there is no immunization for this viral infection or for that matter for any of these non-polio enteroviruses. There is specifically no immunization against any of enteroviruses, including EV68 or EV71.

Type 2: Hand Foot and Mouth Disease Coxsackie A

6: In exactly the same time period, during the winter of 2014-2015 when Amy fell ill, Drs. C Sinclair and E Gaunt et al in Edinburgh identified a cluster of 16 HFM disease patients caused by Coxsackie A6 and published in the medical journal [Euro Surveillance](#) (2014, Mar 27;19,12:20745.0). This Edinburgh cluster was probably the tip of the iceberg. I have no doubt thousands of children and adults in the UK fell ill with this illness and like Amy have been misdiagnosed. The reader can be fairly certain that up to 5% of those patients who fell ill in the UK are now, like Amy, chronically ill, misdiagnosed, and some placed into a psychiatric institution as they tried to do with Amy.

Type 3: Hand Foot and Mouth Disease EV 71: This enterovirus can also cause HFM disease and also herpangina (a more generalized rash). It is also associated

with more severe illness, high-grade fever (body temperature above 39°C like Amy), flaccid paralysis, encephalitis, pain syndromes, aseptic meningitis, cardiopulmonary and neurological complications. A large number of patients have died in Southeast Asia with severe illnesses, including AFP, aseptic meningitis, encephalitis, pulmonary edema or hemorrhage, and myocarditis (heart injury) or worse. Our Amy certainly had one of these infections but her many physicians somehow forgot to test her for enteroviruses, the major cause of HFM disease.

Amy's mother sent me photographs she had taken of Amy, which once again were typical hand foot and mouth disease skin lesion and typical locations. The doctors thought (a) the exterior skin lesions were herpes and (b) the ones in Amy's mouth were due to Amy biting herself. I have no evidence that the physicians in either hospital suggested HFM disease or tested for enterovirus or did a lumbar puncture. Spinal fluid analysis done early in M.E. have demonstrated CNS neuron damage with positive oligoclonal banding. At least two of these HFM viruses were current in England when Amy fell ill with what sounded like an encephalitis. These HFM viruses can and do cause meningitis, encephalitis, acute flaccid paralysis or myelitis and it is difficult to understand why Amy was not at least tested for these severe illnesses.

The description to date, given to me by the mother, was classical of both HFM disease and Myalgic Encephalomyelitis. I had already seen four teachers ill with Myalgic Encephalitis in Canada who had students ill with hand foot and mouth disease. Enteroviruses, depending upon the age of the patient, can give very different degrees of illnesses, varying from unnoticeable, to mild, to severe. The same type of enteroviruses, depending upon the individual infected might cause gastritis, or pain syndromes, pulmonary complications, cardiac disease, paralysis, or death. Enteroviral M.E. is just like polio where most infected patients at first had no visible illness and yet up to 5% of these patients were paralyzed or died.

Still in Canada, I wrote a letter to Amy's hospital doctor and suggested to her mother that she take Amy back to the physician with the letter in which I suggested certain enteroviral tests and an HMPAO brain SPECT, which would demonstrate perfusion brain injury, if this existed, as I believed. This would change Amy's illness from the incorrect psychiatric diagnosis to a physical one.

The parents followed my suggestions and took Amy back, but the specialist stated she wouldn't do any of the suggested tests since they were invasive. In Canada we do these suggested tests on a regular basis and in 30 years we have never had any patient injury. I believe this reply by the UK physician might have represented a tactical position, because if the test was performed and demonstrated significant disease, the physicians would have been embarrassed. So once again neither Amy nor her parents were listened to and were once again dismissed. The doctors had made up their minds and this girl was to be sectioned for psychiatric illness. End of story.

Ethical Problem

There was now a major problem. With an adult ill for almost three years, you can give advice and suggestions. It is then up to the patient to make any decisions.

However, when the patient is a youth now 12 years old, ill without a correct diagnosis for almost three years, if the local physicians aren't interested, what can one do? This is clearly a situation no moral physician should abandon.

So I asked the mother if she wanted me to do a house call. She said yes. So my wife and I flew to the UK and arrived at their home in England on a balmy February day. It just happened to be a school holiday so mum and the three girls were all at home. The following is what I found.

This was a house with an understandably worried mom, two happy and lovely children and a girl who was now 12 years,

stranded by the medical community for over two years. Amy was lying in bed trying to read a book. The dog Winnie and the two guinea pigs, Betty and Primrose were quite contented. The children's father was at work. Except for Amy, they appeared like any above normal intelligence family. Amy appeared a bit timid and withdrawn. Amy's mum told me her daughter had been emotionally traumatized by the several physicians she had encountered, so I decided to spend the first 30 minutes chatting with Amy and her sisters, hoping she would become used to me. Then I asked if I could examine her. Mother and daughter agreed, and with my wife, mum and the two sisters gathered around I examined Amy. According to the mother, during the course of her illness, no physician had seriously examined Amy before.

I started by taking Amy's blood pressure and heart rate. It was relatively normal at 88 beats-per-minute (bpm) with a blood pressure (bp) of 109/76 mg of mercury. These findings would be considered normal for her age, although 88 bpm might be considered to be a bit rapid for someone lying down in bed.

I asked Amy to stand and her heart rate immediately rose to 116 beats per minute (bpm). Much too fast, but it quickly settled down to 105 bpm, still much too fast for someone doing nothing but standing. At the time, I thought this rapid heart rate might be explained as a result of her lying in bed but, since she had been a little more active recently, I doubt that was the cause. I then proceeded to take Amy's blood pressure for 10 minutes and this is what I found.

Time in minutes	Left Arterial Blood Pressure, mgm mercury	Heart rate bpm	Amy is standing 2 inches away from her bed, not talking and trying to stand still. I am sitting immediately in front of her to catch her should she fall or collapse.
In bed	109/76	88	Lying prone
1 standing	118/79	105	Standing at attention, not moving or speaking
2 min.	105/82	110	
3 min.	118/80	118	
4 min.	124/81	129	
5 min.	144/73	128	
6 min.	124/85	133	
7 min.	123/81	130	
8 min.	61/30	81	A precipitous fall in her blood Pressure occurs. Amy loses consciousness and she falls onto her bed. I lift and massage her legs and she regains consciousness within 15 seconds.
		?	

In other words, on an across the ocean SKYPE interview: it took 20-minutes **to suggest** the diagnosis of Hand, Foot and Mouth Disease (HFMD) and 30 seconds looking at the photographs the mother had taken and already shown to the doctors, **to confirm** the diagnosis of classical Hand Foot and Mouth disease.

Then at Amy's home it took a bit of kibitzing, a 10-minute examination and no expensive equipment other than a classical sphygmomanometer (blood pressure cuff) and stethoscope available in every physician's office, to diagnose a **classical dysautonomia** and to definitely classify her with **POTS (Postural Orthostatic Tachycardia Syndrome)**. It is my belief this is a measurable injury of the **insular cortex** area of the central nervous system area which is one of the areas regulating blood pressure, heart rate and normal peripheral artery contractibility. This simple history and examination explained Amy's illness, also her repeated falls and short losses

of consciousness which, along with the classical (HFM) mouth lesions, had been erroneously dismissed as a psychosis

Let me repeat this since it is important in diagnostic medicine: In my experience with SPECT brain mapping, patients with dysautonomia demonstrate a significant hypo-perfusion injury to the **Insular Cortex** area, easily documented with a SPECT brain scan and appropriate Segami Oasis software. I believe this typical dysautonomic injury was what the physicians had misdiagnosed as a seizure.

What is Missing?

We require viral proof Amy's illness was due to hand foot and mouth disease caused by one or more of the viruses listed above. It could have been performed easily at the beginning of Amy's illness. Why wasn't this done by any of her physicians? Really, there is no excuse. The UK has some brilliant enteroviral research centres including (1) St. Thomas in London, (2) Oxford University, (3) Leeds, (4) European Centre for Disease Prevention, (5) Edinburgh, (6) Reading, and the list undoubtedly goes on. There is no indication Amy's stools or gastric mucosa were ever tested for enteroviruses. There is no indication a routine HMPAO brain SPECT was done to diagnose Amy, which would indicate if the brain and insular cortex had suffered injury. This could still be performed if HMPAO is used. There was no gastric mucosa biopsy to demonstrate chronic enteroviral infection. This still could be done. A normal MRI or CT scan doesn't show physiological brain injury. These only demonstrate gross anatomical damage, not micro-vascularization and neuron injury. It is not good enough to say these tests are invasive. This is just an excuse to not do what is necessary to prove a diagnosis and advise the patient and her family correctly. In addition to the brain SPECT it wouldn't hurt to also do a **3 tesla MRI/MRA** of the brain to rule out any other CNS injuries caused by or associated with this infection. At times in adults there is an associated vascular pathology localized in the same area. (MRA is a magnetic image test of the brain's blood vessels.)

The only good news is that Amy is young. Given time, she will

slowly improve and hopefully get back to school to achieve great things. If she were in her twenties to forties, after two years there would be a lower chance of significant recovery. In adults, untreated chronic disease can cause its own permanent disabilities. In children, depending upon the degree of injury, this is less likely to occur. Because no appropriate tests were done we do not know the extent of the injury.

Amy also represents a typical severe case of Myalgic Encephalomyelitis (M.E.), a significant central nervous system hypo-perfusion injury causing major cognitive and administrative brain dysfunction. **Every one of my M.E. patients have a significant and usually severe hypo-perfusion injury of the left anterior temporal lobe**, and particularly the area known as Brodmann 38. *But once again, no diagnostic brain SPECT was ordered for Amy.*

Unfortunately, M.E. is a severe CNS illness dismissed by too many physicians. Amy also represents a typical case of Myalgic Encephalomyelitis, caused by the same enteroviruses that caused Amy's Hand, Foot and Mouth Disease. This is not simply a criticism of UK physicians, it is a diagnosis missed by too many physicians not just in the UK but in much of North America and Europe.

This is a typical story of **Matryoshka Dolls**, one puzzle inside another, explained by the following equation:

**Acute Illness → Enteroviral Infection → Hand Foot and
Mouth disease
→ Chronic brain hypoperfusion injury of the temporal lobe
and limbic system →
M.E. → Dysautonomia**

Amy's illness might be viewed as a typical and dangerous case of child neglect, not by the parents, but by the British medical community that was supposed to serve her best interests and the best interests of all children and adults in the United Kingdom.

It is obvious Amy cannot go to any school with untreated POTS. Although she could have good home schooling provided by the state, it has not been provided. My assessment of the mother and children is that they are all of above normal intelligence but that neither adequate medical assistance, nor educational assistance has been provided for Amy. The family only required normal and correct medical help, a simple history, a simple medical examination and a basic knowledge of infectious disease by her physicians. Yet this normal care was not delivered, by the medical health services and the 14, perhaps too busy, physicians who failed to properly take a history or to adequately examine this child or to come to the correct and obvious diagnoses.

The question remains: why did Amy's multiple physicians fail Amy? Some U.K. patients believe that British physicians are obliged to follow a quota system and must see too many patients each day. I don't know if this is a valid belief. Britain has great physicians but obviously mistakes were made.

**Further Notes on the 6th of March 2010 Meeting
The Westminster Talk to the Committee of the House of
Commons and Lords.**

Myalgic Encephalomyelitis (M.E.): M.E. is not a myth. It was investigated, very well described and championed by many brilliant physicians, including the following:

Sir Donald Acheson, KBE, who was the late Chief Medical Officer of The United Kingdom, (1983-1991)

Alexis Shelokov in the USA, a co-inventor of the Salk polio immunization and Director of Vaccine Research, and member of the President's White House Scientific Committee and by

A. Melvin Ramsay who supervised the care of the nurses, physicians and health care workers who fell ill with M.E. at the Royal Free Hospital in London during the combined polio and M.E. epidemic in 1955.

The cause of M.E. is not a myth. In the over 60 documented epidemics of Myalgic Encephalitis, the only causative viruses recovered, were enteroviruses. The majority of M.E. sporadic cases occur from June to December, the same period when enteroviruses do most of their harm in the north temperate zone. When known, in M.E. and paralytic polio epidemics the lowest incubation period tends to be from 3-6 days.

M.E. is not a myth, nor is it Chronic Fatigue Syndrome. M.E. is a well-known epidemic and sporadic enteroviral disease that prior to the invention of polio immunization in 1955, tended to occur at the same time and in the same location as paralytic poliomyelitis. M.E., like polio, is a biphasic enteroviral disease, acting much like the three enteroviruses known as polioviruses. They enter the body through the gastric tract (GIT), then spreading to the entire body but specifically to the central nervous system or to the heart. However, whereas polio primarily injures the brain stem and spinal cord causing death or paralysis and to a much lesser degree an injury to the brain itself, the several M.E. enteroviruses noted earlier in this paper, tend to primarily injure the brain above the brain stem causing a variable chronic encephalitic condition. To a lesser extent they also injure the brain stem and spinal cord. This variable chronic brain injury of M.E. depending upon where and how severe the brain injury may be, can scramble and disable the brain's memory, retrieval, processing centres, pain and balance centres, and in worst case scenarios, the autonomic nervous system.

Chronic Fatigue Syndrome: CFS is in many ways a non-disease. It was reputedly the invention of the late Dr. Stephen Straus of the National Institute of Health in Bethesda, Maryland. When I was invited to speak to the House of Lords and Common's committee, I noted that Chronic Fatigue Syndrome or CFS had such a multitude of changing diagnostic criteria due to the fatal errors in this original first Straus definition. Dr. Straus's ideas were published in 1988 as: *Chronic Fatigue Syndrome: A Working Case Definition*. The definition was based upon the erroneous view that the Lake Tahoe M.E. epidemic in August of 1984 was

an epidemic illness caused by Epstein Barr Virus (EBV). (EBV is the primary cause of what is called Glandular Fever in the UK and in North America called Infectious Mononucleosis.) To attest to the perfection of the Straus definition, 16 eminent “physicians” and researchers signed this document published in the Annals of Internal Medicine. Curiously, the majority of the 16 were not physicians, nor had the majority ever seen any kind of patient and more specifically, with few exceptions, had never seen a patient with the so-called Chronic Fatigue Syndrome.

Stephen Straus, the reputed inventor of this term, was also (1) one of the three secret peer review members of the renowned and excellent New England Journal of Medicine and also (2) the chairman of the NIH money-granting body overseeing CFS grants. As a member of the peer review he blacklisted the excellent paper by Dr. Dan Peterson et al, one of several physicians who had first-hand knowledge of the Lake Tahoe epidemic. I believe well over **40-60 million dollars** was then dispensed to many of the 16 members who first signed Stephen Straus’s definition and to his academic friends. Tragically, if a researcher didn’t support the Straus faulty definition, they received no NIH grant. I believe a whole lot of scientific misinformation then occurred in order to first obtain grants but ultimately to actually invalidate their findings, since no such disease exists. The first signatory of the definition, Dr. Gary P. Holmes, was a PhD student at the Centers of Disease Control and Prevention, (CDC), who then left to practice medicine in Texas, and as far as I know received not a penny. Why? In 1987, Holmes produced an honest research paper essentially stating Steven Straus’s theory was erroneous and EBV had nothing to do with the epidemic in Lake Tahoe. This caused Dr. Straus to blow up in my presence on receiving the news of Holmes’s publication. Holmes then immediately left the CDC and for all practical purposes never again looked at the mythical “CFS.”

CFS doesn't exist but represents many undiagnosed, serious debilitating diseases that have not been diagnosed adequately or at all. Some of these

desperately and chronically ill patients have M.E. Some have one or multiple missed significant illnesses. Too many have been falsely dismissed as psychiatric patients or anxiety neurosis. Rarely are any psychiatric patients. Like Amy, they too are in need of care.

Meanwhile, the wonderful Amy Brown, lies at home, not abandoned by her family, but abandoned and misdiagnosed by her physicians and unfortunately, also by England.

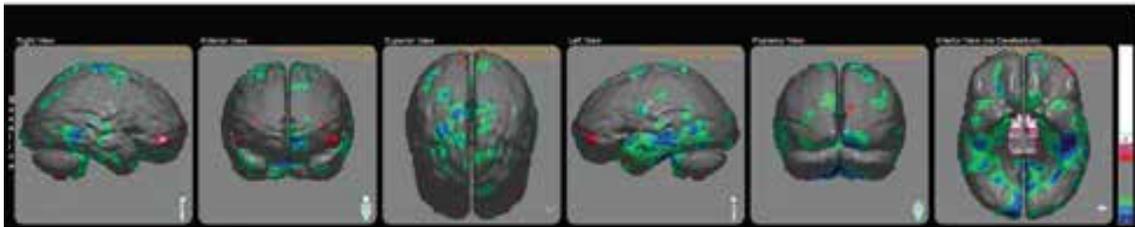
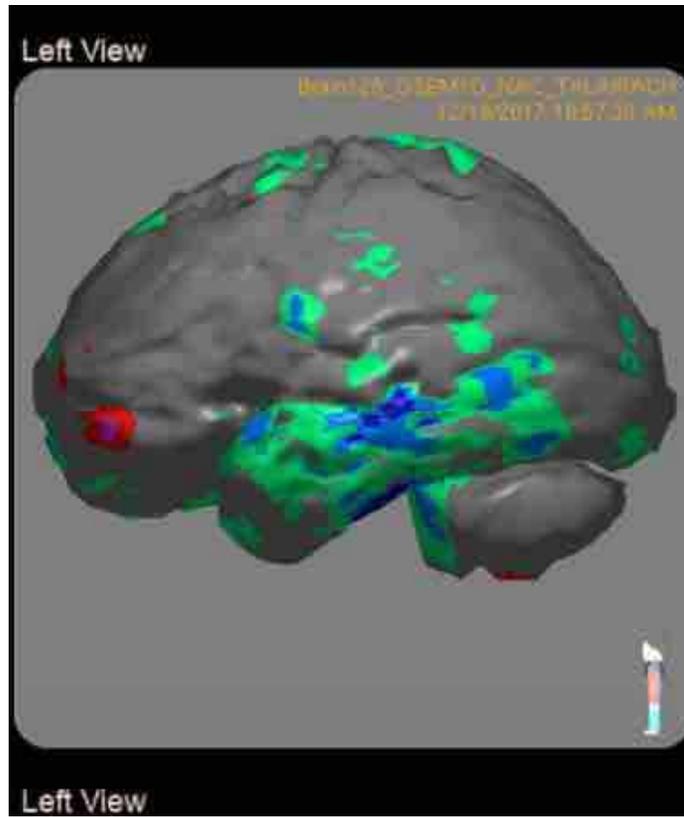
This includes a total of 6 brain images demonstrating significant brain hypoperfusion injury.

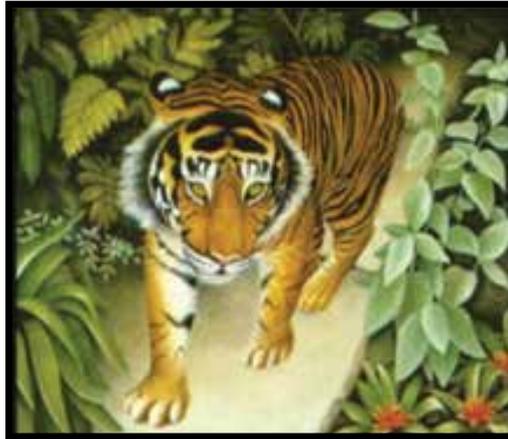
Amy's resting HMPAO SPECT brain map demonstrates extensive injury to:

Left Cortex, Left Temporal Lobe. This is the lobe responsible for all information recall. The entire temporal lobe is severely damaged and probably accounts for the severe headaches she experienced early in her enteroviral encephalitis caused by the Hand Foot and Mouth disease.

The Cerebella Vermis: responsible in part for Postural Orthostatic Tachycardia Syndrome (POTS). This area is severely damaged.

Spotty injury to the motor cortex and Parietal Lobe.





**The Nightingale Research Foundation
Ottawa, Canada
<http://www.nightingale.ca>**

We chose the Tiger, a natural killer, as our logo because one of the first scientific benchmarks of M.E. and CFS was the fact that patients lacked active natural killer cells, an essential part of the immune system.

We chose Nightingale as our name in honour of Florence Nightingale who fell ill with an infectious disease during her service in the Crimean War. Despite her severe disability, she went on to reform both public health and health care, helping to bring medicine and especially the care and treatment of the ill patient into the Twentieth Century.

You may purchase copies of this M.E. definition booklet from:
office@nightingale.ca (see inside front cover)

www.nightingale.ca

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