

Post-Polio and Post-M.E. New book furthers polio hypothesis

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A CFIDS activist, Jane Colby is on the UK National M.E. Task Force, gives lectures and media interviews and regularly advises UK CFIDS charities. In April 1996 she and TV personality Esther Rantzen launched their M.E. Children's Charter for the UK organisation *Action for M.E.* Her Children's Charter and other information about CFIDS/M.E. can be found on her website at <u>http://www.jafc.demon.co.uk</u>

The following is an excerpt from the recently published book *M.E. The New Plague* by Jane Colby, a former school principal turned writer and researcher. The book, reviewed on page 55, uncovers strong evidence that myalgic encephalomyelitis (M.E., the British term for CFIDS) is a type of polio which has, by historical accident, been given another name. Jane warns that we are repeating the mistakes of the past, which have led to further illness in polio survivors decades later. She also includes a risk factor list, survivors' lifestyle checklist, schools guidelines, comparisons of M.E. with school phobia and a chapter on psychological survival. Jane interviewed numerous experts including Dr. Richard Bruno, a post-polio researcher at the Kessler Institute in New Jersey. <u>To order *M.E. The New Plague*</u>, see item #3240 on page 63.

By altering the population's resistance to a particular organism, we alter the balance of infectious agents in the environment. Most of us are resistant to polio viruses 1-3 through vaccination. But we have not been immunized against the many other polio-related viruses [such as Coxsackie].

It is therefore not surprising that since the late 1950s the incidence of M.E. has risen and risen, and experts predict that it will turn out to be the commonest neurological disease of the 20th century. Indeed, it has already been estimated that the total M.E. cases in 1987 equal the 1952 polio cases. By suppresing the spread of these enteroviruses we have opened the door to the rest.

It can be observed through case histories that, just as we see post-polio syndrome 30 years after initial polio infection, so we are seeing what I have called "post-M.E." as well, in people who got M.E. as youngsters.

A proposition from the Nightingale Foundation in Ottawa is that, in fact, M.E. and post-polio are one and the same condition. What has arisen is:

"Two new diseases with different names, with different degrees of acceptance and exactly the same set of symptoms at exactly the same time. It is unrealistic to believe that we are dealing with two different disease processes and two different causes." [1]

Alternatively, and because of the difference in the detail of symptoms between post-polio people and those with M.E., we might be able to say that M.E. in youngsters is the equivalent of acute polio in youngsters, and that post-M.E. (in sporadic adult cases) is the equivalent of post-polio, developing years after the original infection.

If M.E. and polio are enteroviral conditions, simply variations upon one another, then the "sequelae," or later complications, are post-enteroviral conditions. This has far reaching implications. Around 90% of polio survivors have gone on to develop post-polio syndrome. It has been predicted that this will eventually rise to 100%. [2]

In addition, those children who, back in Iceland in 1948, developed M.E. (then called Iceland disease) were followed up decades later and the majority still had symptoms.

[Post-polio expert] Dr. [Richard] Bruno points out that physical over-activity is the biggest cause of post-polio symptoms. [3] (See Dr. Bruno's <u>"Fainting and Fatigue"</u> in the Spring 1996 Chronicle, page 37.)

What are we doing to our teenagers with M.E. when we force them back to school, deny them home tuition and tell them to exercise as a form of therapy?

We know that muscle cells in M.E. have faulty "battery" mechanisms and that energy cannot be readily regenerated. The aerobic/anaerobic cycles are disrupted, so that if we overwork muscles affected by M.E., the fibers that can work without oxygen, and that are there for use in emergencies, get over-used, potentially causing damage.

It is well-known amongst people who are trying to get over M.E. that exercise, often undertaken early on in the disease in attempt to get fit again, can make them a great deal worse. This is partly because the muscles are not able to function like healthy muscles. But knowledge of the behavior of enteroviruses goes even further towards explaining why this should be.

Right back in 1970, it was shown by Gatmaltan, Chason and Lerner that when mice infected with Coxsackie B3 were forced to swim in a warm pool, the virulence of the virus was drastically augmented. In fact, viral replication was augmented 530 times. This did horrendous things to the animals' hearts. We all know that to play squash with the flu can lead to heart attacks. Much the same danger can be courted by undertaking hard exercise with M.E.

In 1988, Reyes and his colleagues exercised mice suffering from Coxsackie B3 myocarditis -inflammation of the heart muscle caused by the virus. They showed that the effect of exercise on the production of the neurohormones which regulate immune response and inflammation led to an increase in susceptibility to Coxsackie virus infections -- the host response was altered in favor of the virus.

Roger Loria, discussing not only these very grave findings, but also those of Jamal and Hansen in 1985, who reported that abnormal single-fiber electromyographs (muscle graphs)

were evident in 40 patients with postviral fatigue syndrome (PVFS, analogous to M.E.), 35 of whom had a Coxsackie infection, said: "These observations, as well as the recent interest in postviral fatigue syndrome (M.E.) may have considerable application." [4]

The year in which he said this was 1988. We seem still to be waiting for someone to apply them.

The treatment of choice for those with post-polio is: "adequate rest, energy conservation, the pacing of activities, and reducing physical and emotional stress." [5]

What on earth will happen in 30 years' time to children now getting M.E. in a climate where they are disbelieved and told to push themselves through the pain barrier? The condition "post-M.E.," which we may already be seeing in adults, could well await them with a vengeance.

The seriousness with which we take M.E. ought to parallel the seriousness with which we regarded polio. Byron Hyde and his team speak for us all:

"There is a myth among large numbers of physicians... that this is a short-term illness. We have reviewed the literature and can find no published study that supports the thesis that M.E./C.F.S is an illness of a short duration...

"Clinically, after the first year of illness, we have seen recoveries, but they have been the exception rather than the rule. We attempted to verify this and asked our 1,826 respondents to note the degree of their recovery over the period of their illness. Our survey group's average length of illness was approximately seven years.

"The findings... demonstrate that, in this entire group, there has been only 2% recovery. The 2% total recovery of treated M.E./CFS patients suggests that the large number of pharmaceuticals, alternative medicines and various treatments used have been largely ineffective." [1]

Dr. David Bell, a clinical instructor in pediatrics at Harvard Medical School, has noted that from, a group of 40 children with M.E., those with less severe symptoms, perhaps not surprisingly, were the most likely to have "recovered" three years later. Those children who were the most ill at onset "were in general ill three years later." [6]

That was in 1989. It is not known whether symptoms will recur in the distant future. But two adults being studied by Dr. Bell's team had been ill as teenagers, "recovered" after one year, but "subsequently developed the same symptoms up to 20 years later."

As we shall see in further chapters [of *M.E* -- *The New Plague*], the way in which we live our lives may well affect both the extent and the likelihood of a return of symptoms. But people who do not take a disease seriously or who do not know of its potential to cause later trouble are not being given the chance to take this step.

We now know that M.E., or atypical polio, is a serious and devistatingly debilitating, multisystem malfunction leading to such profound weakness in some children that they are unable to speak and have to be tube-fed. There is accumulating evidence to suggest that it is a potentially a life-long condition. However [unlike those with polio], these children can breathe; enteroviruses have an affinity for certain tissues and many do not attack the respiratory centra causing death.

In spite of the enormous body of evidence accumulating which links M.E. and polio, we are still seeing many M.E. patients disbelieved, exercised and treated as if it were only their own mental set which militated against recovery.

Is this simply because we cannot actually point to rows of coffins and iron lungs?

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