Quest #52 March 2002

National ME/FM Action Network of Canada is proud to sponsor the

1st Annual Symposium on

Parallels Between Post-Polio Sequelae, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia

June 15, 2002

1:00 – 4:00 P.M.

Holiday Inn Hotel & Suites Toronto-Markham, Ontario

TICKETS:

$8.00 in advance or $10.00 at the door.

To reserve a seat, please contact: **Mary Ellen**, **National ME/FM Action Network**, P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON L1V 6P7. Tel/Fax: **(905) 831-4744**

E-Mail: **marye@pathcom.com**.

12 noon - 12:50 pm Registration

PLEASE NOTE: Refreshments will be sold during the registration period as there will not be time for participants to purchase them during the 15 minute "rest" break. Water will be available at the tables. Refreshments and snacks will also be sold from 4:00 - 5:00 pm.

Why Polio and PPS?

Dr. Richard Bruno, one of our speakers, has been researching the late effects of polio (also known as post-polio sequelae or post-polio syndrome) for twenty years. What Dr. Bruno and others have found has led to Dr. Bruno starting a worldwide awareness campaign, trying to reach polio survivors, doctors and governments.He says: "There is no more time to waste" because people who had polio in the years before the vaccine became available are aging and many are experiencing terrible deterioration in their functioning. Many have to go back to using assistive devices and can no longer work. Research shows these patients' neurons are dying. Dr. Bruno is referring to muscle neurons but also brain neurons. Not many people realize that the poliovirus targeted the brain stem and caused an "encephalitis" (brain infection). This brain stem damage can get worse with physical and mental stress and, in Dr. Bruno's view, this is what leads to many of the symptoms of PPS. When the neurons die, functioning gets worse unless the people slow down and get proper care.

New Research on Parallels Between PPS and ME/FM

Now about ME/CFS: Dr. Bruno's research has shown many parallels in signs and symptoms between PPS and ME/CFS. The most important parallel is in the brain. Research shows that many viruses can damage the brain stem. Here enters the work of Dr. Elizabeth Dowsett, our other speaker, a doctor and researcher with thirty years of experience with people with ME/CFS. In January 2001, Dr.Dowsett gave a presentation on the parallels between PPS and ME to the British Parliament.

Implications for Assessment of Disability and for Treatment

Dr. Dowsett believes that the polio vaccine made room for other polio-like viruses (from the family of viruses called enteroviruses) to take over. According to Dr. Dowsett's research and other work, these other viruses may even hit some parts of the brain harder than in polio, judging by the brain fatigue and research on the ME/CFS brain. So, even if people with ME/CFS don't have paralysis and get as physically weak as people who had polio, they may be even more impaired in other ways. This has VERY IMPORTANT implications for assessment of disability and for treatment.

Important Treatment Information

Dr. Bruno says pacing, NOT cognitive behavioral therapy and NOT graded exercise, is the cornerstone of treatment for people with PPS and ME/CFS. The key message is that people with ME/CFS and PPS and some people with FM have demonstrated brain stem dysfunction. This explains a multitude of symptoms because the brain stem controls so many physical and mental processes. Dr. Dowsett supports this view.

We Invite You to Join Us

At the National ME/FM Action Network, we are interested in learning more about this very promising research. We are delighted to offer you the opportunity to listen to the research findings of Dr. Bruno and Dr. Dowsett and learn first-hand about the striking parallels between PPS, ME/CFS and FM. We look forward to your participation in this symposium.

For further information, please see our Symposium webpage :**www.geocities.com/canadianyouthmefm/symposium.htm**

THE CANADIAN CONTRIBUTION TO THE POLIO AND ME/CFS/FM CONNECTION – By Kate Anderson, M.Ed.

QUEST readers will know that the **National ME/FM Action Network** assisted **Dr. Richard L. Bruno's** to distribute an international survey exploring links between a childhood illness and symptoms of ME/CFS and FM later in life. On June 15, 2002, Drs. Bruno and Dowsett will be the speakers at the **1st International Symposium on Parallels Between Post-Polio Sequelae, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia**. Kate Andersen is the Manager of Public Relations for this symposium. She interviewed Dr. Bruno about his work leading up to the survey as well as about the findings and their implications.

Kate: Maybe we should start by reviewing why you conducted this survey in the first place.

Dr. Bruno: Since 1999 I have wondered if polio might be related to chronic fatigue syndrome in baby boomers. A 1999 epidemiological study by Lenny Jason found that half of the estimated 836,000 Americans with chronic fatigue syndrome are at least 40 years old. Jason concluded that baby-boomers may be at greater risk for ME/CFS. I thought that baby boomers' greater risk might be related to their having had a poliovirus infection since they would not have been vaccinated against polio until at least 1955, when the newly developed Salk vaccine was distributed.

We found that twenty percent of chronic fatigue patients born before 1955 were able to remember an illness with a fever, typically in 1947 when they were seven -- the average age of a polio patient in 1947. Just over one-third recall having had a stiff neck -- the first "red flag" symptom of polio -- about one-third were hospitalized and 70% remember having had muscle weakness. Remarkably the distribution of childhood illness cases in the Survey was nearly identical to the distribution of reported polio cases in the US and UK between 1935 and 1955.

What is more, ME/CFS patients who remembered a childhood illness are more affected than ME/CFS patients who did not remember an illness or even polio survivors with PPS: they reported more difficulty with concentration, thinking clearly, word finding and joint pain, are more affected by emotional stress, have had more episodes of fainting, and are more likely to have sleep disturbed by abnormal breathing and muscle twitching.

Kate: How would the poliovirus cause symptoms in ME/CFS patients that sound just like PPS?

Dr. Bruno**:** It has been known since 1947 that the poliovirus damages brain stem neurons that activate the brain – the 'brain activating system' that keeps the brain awake and focuses attention – whether or not it damages spinal cord neurons that move the muscles. Those diagnosed with so called 'non-paralytic' polio had sometimes severe damage to the brain activating system, and can have fatigue today, even though they had no paralysis. These findings are consistent with the hypothesis that ME/CFS (also known as M.E. or myalgic encephalomyelitis) arises from a 'silent' attack of a virus or other agent that targets the brain stem. But we thought that it was indeed the poliovirus that damaged brain activating neurons and causes the signs and symptoms of fatigue in both polio survivors and baby boomers with ME/CFS.

Kate: Do you think that non-paralytic poliovirus was responsible for outbreaks of ME/CFS before the polio vaccine?

Dr. Bruno: There are amazing historical connections and physical parallels between polio and ME/CFS. There is a nearly 70 year history of ME/CFS outbreaks occurring at the same time as polio epidemics. Between 1934 and 1954 -- the year the polio vaccine was developed -- nine ME/CFS outbreaks occurred either at the same time as polio epidemics or affected the staff at polio hospitals. In fact, the first documented ME/CFS outbreak was in 1934, sickening the staff of the Los Angeles County polio hospital.

The two most remarkable epidemics showing the poliovirus/ME/CFS relationship was in September of 1948. Three cases of paralytic polio were diagnosed in the small city of Akureyri, Iceland. And although not another case of polio was reported, over the next few months more than eleven hundred Icelanders reported typical polio symptoms -- fever, neck pain, muscle weakness and even some paralysis -- as well as tingling, numbness and "general tiredness," symptoms not associated with polio. Neither the poliovirus nor poliovirus antibodies were found. Yet, doctors in Iceland concluded that there were only two possible causes for what has come to be known as "Iceland Disease:" Either a strain of poliovirus of low virulence was responsible for the epidemic or some unknown neuron-damaging virus has been present.

Hard evidence for a "non-paralytic" poliovirus causing Iceland Disease came six years later. In 1955, there was an extensive polio epidemic in Iceland caused by the Type I poliovirus. In addition, there were two new outbreaks of Iceland Disease. Remarkably, not one case of polio was reported in towns where there was Iceland Disease in spite of the fact that only 7% of the children in those towns had Type I antibodies. Equally remarkable, 100% of children in the Iceland Disease towns had antibodies to Type II poliovirus, as well as high levels of antibodies to the rare Type III poliovirus. Apparently, children in Iceland had been exposed to a "non-paralytic" Type II poliovirus that damaged their nervous systems and caused symptoms of Iceland Disease, but prevented infection by the Type I paralytic poliovirus.

Kate: If a "non-paralytic" poliovirus can cause ME/CFS, why couldn’t the "non-paralytic" poliovirus used in the Sabin oral polio vaccine cause ME/CFS?

Dr. Bruno: There is absolutely no evidence that the polio vaccine itself causes ME/CFS. But eliminating the natural supply of poliovirus through vaccination may have. Something unexpected, frightening and totally unrecognized happened after the polio vaccine was distributed: the number of cases of ME/CFS went through the roof. British ME/CFS pioneer Dr. Elizabeth Dowsett reviewed the 2,500 ME/CFS patients she and Dr. Melvin Ramsay had seen since 1919, and plotted the cases of ME/CFS against reported cases of polio. When the Salk and Sabin vaccines brought the yearly number of British polio cases below 25 in the early 1960s, the number of ME/CFS patients took off. In Ramsay's and Dowsett's practice alone, between 1960 and 1980 the number of ME/CFS patients increased by fifty fold. Between 1980 and 1990, the number of patients with ME/CFS increased yet again by a factor of fifty! Throughout the world, 32 ME/CFS outbreaks were recorded after the polio vaccine was distributed.

Kate: How would the *lack* of poliovirus cause ME/CFS?

Dr. Bruno: Dr. Dowsett thinks that the elimination of poliovirus left a vacuum that had to be filled by another enterovirus -- a virus that multiplies in your intestines -- similar to the poliovirus that also damages the brain activating system. In 1990, Dr. Dowsett looked for antibodies to non-polio enterovirus in her ME/CFS patients. Fifty percent had antibodies to the first non-polio enterovirus ever discovered, the Coxsackie B virus, named after Coxsackie, New York, the town where it was found to have paralyzed children in 1948. It is not just the polioviruses that enter and kill neurons in the spinal cord and brain activating system. Neuron damage, weakness, paralysis and symptoms of brain fatigue caused by other enteroviruses can be so similar as to be indistinguishable from the actions of the polioviruses. Other non-polio enteroviruses that cause damage and symptoms similar to the polioviruses include all the other Coxsackie viruses, the ECHO viruses (which in 1956 were the first viruses associated with an ME/CFS outbreak), Enteroviruses 71, and viruses that cause illnesses evoking far away places with strange sounding names: Central European Encephalomyelitis, Australian X, Japanese B and St. Louis Encephalitis. So there are many viruses that could take the place of the poliovirus , damage the brain activating system and cause ME/CFS.

Kate: This history is fascinating. But what about the new research on ME/CFS? How does your work on PPS and ME/CFS contribute to the evidence that ME/CFS is physical not an emotional, illness?

Dr. Bruno: We and other researchers have found remarkable similarities between the signs and symptoms of post-polio brain fatigue, ME/CFS and even FM. We found that polio survivors with fatigue have evidence of damage to the brain stem neurons that activate the brain -- the "brain activating system" -- that keeps the brain awake and focuses attention -- is identical to abnormalities seen in patients with ME/CFS.

Kate: Could you tell our readers the major findings?

Dr. Bruno: Our studies and those of other groups have found that:

- Polio survivors and ME/CFS patients report disabling fatigue that is triggered or made worse by physical exertion and emotional stress;

- Polio survivors and those with ME/CFS have the characteristics of the hard-driving, pressured, time-conscious, perfectionistic, overachieving Type A personality;

- Nearly half of polio survivors and ME/CFS patients have sleep apnea or hypopneas;

- Polio survivors and ME/CFS patients have belly problems, including decreased movement of the intestines;

- In polio survivors and ME/CFS patients there is a relationship between fainting and having fatigue. In both groups purple feet indicate that blood pools in the leg veins and there is evidence of damage to the nerves that control the blood vessels;

- Polio survivors with fatigue and ME/CFS patients report difficulty with attention, word finding, thinking quickly and memory. On neuropsychologic testing, attention and word finding are abnormal and the ability to think is slowed in fatigued polio survivors and in those with ME/CFS, test scores in the two groups often being identical;

- Eighty-five percent of patients with ME/CFS have brain wave slowing similar to that seen immediately after polio and that we have found in polio survivors reporting fatigue;

- Brain MRI shows lesions in the white matter in nearly 50% of fatigued polio survivors and in from one quarter to 100% of ME/CFS patients. These lesions are similar to, although are smaller than, but found in the location in the brains of multiple sclerosis patients who have fatigue and difficulty with attention;

- Gray matter lesions in the brain activating system have not been seen on MRIs in ME/CFS patients, as they have in polio survivors with fatigue. However, a new brain imaging device -- the SPECT scanner -- has found that ME/CFS patients have decreased activity of neurons in the brain stem, the neurons that are at the center of the brain activating system;

- Fatigued polio survivors and ME/CFS patients release significantly less of the brain activating hormone ACTH;

- More prolactin is released in fatigued polio survivors and those with ME/CFS, suggesting that less of the main brain activating neurotransmitter dopamine is being produced in both groups. Recently U.S. veterans diagnosed with Gulf War Syndrome who report symptoms similar to those of post-polio brain fatigue and ME/CFS were also found to have lower brain dopamine.

Kate: I understand that one of your most significant contributions to our understanding of PPS and ME/CFS is your model of "a brain fatigue generator." Can you explain this, please?

Dr. Bruno: The striking parallels between the history, signs, symptoms and physiology of post-polio fatigue and ME/CFS caused us to propose the Brain Fatigue Generator Model of all post-viral fatigue syndromes. The Brain Fatigue Generator Model says that feelings of fatigue are normal and are generated naturally when neurons in the brain stem and basal ganglia become "tired" during the course of the day. These neurons stop stimulating the brain and the result is the feelings of fatigue -- difficulty paying attention, not wanting to get our of a chair -- and the overwhelming desire to just slip between the sheets and go to sleep. After a good night's rest, the brain activating system neurons recover and fatigue disappears. But chronic fatigue syndrome is not natural and is not relieved by sleep, because fatigue is generated when brain activating neurons have been damaged by a virus, such as the poliovirus or a Coxsackie virus.

Kate: How has this theory been received by the ME/CFS research community?

Dr. Bruno: ME/CFS researchers were excited by our model of viral damage to the brain activating system causing chronic fatigue because of the parallels between post-polio fatigue and ME/CFS, and because with post-polio fatigue we have a complete system: we know the signs and symptoms of fatigue, we know the virus that damaged brain activating neurons and have autopsy evidence of that damage. Thus far there is no autopsy evidence of brain activating system damage in ME/CFS. In 1995, we were asked to present the BFG model at the First World Congress on Chronic Fatigue Syndrome in Brussels.

Kate: Dr. David Bell was very impressed with your work, saying in "The CFIDS Chronicle":

What seems extraordinary is the similarity of the residual deficits caused by poliovirus and the clinical symptoms present in chronic fatigue syndrome (ME/CFS). The similarities are tantalizing. For years we have been looking for anatomic model of chronic fatigue, particularly post-infectious fatigue. Is it possible that the post-polio syndrome is an example of ME/CFS caused by a specific infectious agent? The work by Dr. Bruno and co-workers may become immensely important not only to the many persons who suffered polio but to those with ME/CFS as well.

Dr. Bruno: David’s work is ground-breaking itself and parallels our own, for example in terms of similar blood pressure regulations problems in ME/CFS and polio and ME/CFS in young people.

Kate: You performed the first study of the psychophysiology of ME/CFS in young people. Dr. Dowsett was also involved with that work?

Dr. Bruno: Oh, yes. Dr. Dowsett is an ME/CFS pioneer in so many ways. On the way back from the 1995 ME/CFS conference in Brussels I first met Betty in London. She told us first hand of her research on ME/CFS and her clinical experience, not only with adults but also with children. In spite of our knowing about the Summer Grippe and Iceland Disease, it had never occurred to us that young people were getting ME /CFS today. Her experience with children echoed what to us was a familiar and disturbing past.

In 1995 she sent questionnaires to nearly 3000 British schools and surveyed 330,000 children! She found that nearly 10% had an illness that appeared to be ME/CFS. Half were unable to go to school and had to be tutored at home and the rest required modified class schedules because of "brain fatigue:" difficulty with word finding, focusing attention, thinking clearly and staying awake during the day. These symptoms reminded us of the high school students with Iceland Disease and even more of Edith Myers' description of kids who returned to school after having had polio, who, she found to have "fatigability and fleeting attention" as well as short attention spans and difficulty in concentration when they were given neuropsychologic tests.

Kate: How did you feel when you heard about this work?

Dr. Bruno: The parallels between Betty Dowsett's findings in children with chronic fatigue, young people with Iceland Disease and polio survivors were too great to be ignored. When we returned to the U.S. I applied to the CFIDS Association of America and received a grant to perform the first study of brain functioning in young people with ME/CFS. We studied a baker's dozen of subjects who were on average 16 years old, who met the 1994 Centers for Disease Control criteria for ME/CFS and who had no psychological problems, plus 10 non-fatigued young people. The more fatigued the kids with ME/CFS were, the more difficulty they reported staying awake during the day, concentrating and focusing attention. We gave all of the subjects the tests of attention, concentration, thinking and memory that we have used since 1991 to study fatigue in polio survivors. As we have found in adult polio survivors with fatigue and others have found in adults with ME/CFS and as Edith Myers found in young people who had had polio, scores on four neuropsychologic tests of attention were abnormal in the ME/CFS patients, while scores on two additional tests of attention were significantly lower in the ME/CFS group. The greater the ME/CFS patients' reported fatigue the worse was their ability to focus attention.

With this study the circle had been completed. Individuals with chronic fatigue -- be they adults or young people, polio survivors or those with ME/CFS -- share an inability to focus attention. We think the simplest explanation for these findings is the Brain Fatigue Generator Model: that viruses damage the brain's activating system, impair attention and cause the signs and symptoms of chronic brain fatigue.

Kate: Is all of this work published in well-known, peer-reviewed journals?

Dr. Bruno. Yes. All of these findings and the idea that a childhood poliovirus infection may cause chronic fatigue in baby-boomers were published in a number of journal articles and are also described in detail in **The Polio Paradox: Uncovering the Hidden History of Polio to Understand and Treat "Post-Polio Syndrome" and Chronic Fatigue** to be published by Warner Books in June, 2002.

Kate: Our readers will know that both you and Dr. Dowsett will be speaking at our upcoming symposium on June 15, 2002 in Toronto on the Parallels between Post-Polio Sequelae, ME/CFS and FM. Are Dr. Dowsett's views different from yours?

Dr. Bruno: Dr. Dowsett believes some enterovirus is still hanging around in the body and "flares up" to cause increases in symptoms. We are of the "hit-and-run" school, believing that viral damage years ago set t he stage for chronic symptoms and increases in symptoms. But we are on the same page in terms of treatment

Kate: What is the treatment for ME/CFS?

Dr. Bruno: It's the same as for PPS, "The Golden Rule: " If anything causes fatigue, weakness or pain DON'T DO IT! (Or do much less of it.) Dr. Ramsay himself said, "The basic fundamental tenet of the management of a case of ME is REST with graduated activity well within the limitations which the disease imposes." Two studies have found that fatigue in ME/CFS is not the result of "deconditioning" brought about by too much rest. And a recent British survey of over 2000 people with ME/CFS found that pacing reduced symptoms in over 80% while exercise increased symptoms in 50%.

Unfortunately, there are doctors who choose to ignore more than 80 years of research suggesting that ME/CFS is very likely caused by one or more of the enteroviruses. Even more than polio survivors with PPS, those with ME/CFS have been dismissed as lazy, crazy or outright liars by the medical community. Maybe it's our Puritan heritage, but there are two symptoms by which we are not allowed to be disabled: pain and fatigue. It's time that doctors read the medical literature on these conditions and discover that these are medical-- not mental -- illnesses.

Kate: I agree. As you know, the **National ME/FM Action Network** represents Canadians with fibromyalgia, too. What's the connection between PPS and ME/CFS and FM?

Dr. Bruno: Fibromyalgia is a syndrome of muscle and joint pain that is defined by specific areas of tenderness to touch, called "tender points," in specific locations: over the buttocks, upper chest, knees and elbows, as well as in the hip, back, shoulder and neck muscles. Because fibromyalgia patients frequently have chronic fatigue, and ME/CFS patients have "myalgia," some specialists believe that ME/CFS and fibromyalgia are the same condition, even though not all ME/CFS patients have pain and not all fibromyalgia patients have fatigue. However, the similarities between the two conditions are remarkable, as are the parallels between fibromyalgia and PPS:

- Polio survivors report joint, muscle neck and back pain at least as frequently as do those with fibromyalgia.

- The neurochemical enkephalin, the body's own morphine, is decreased in fibromyalgia patients. Neurons in both the brain and spinal cord that produce enkephalin were killed by the poliovirus. Lower levels of enkephalin may explain both fibromyalgia patients' increased sensitivity to touch at tender points and our finding of polio survivors doubled sensitivity to pain.

- More prolactin is released in fibromyalgia patients, as has been found in those with ME/CFS and as we have found in polio survivors with fatigue.

- Fibromyalgia patients have decreased activity in neurons in the basal ganglia, thalamus and brain stem, parts of the brain activating system damaged by the poliovirus and whose activity is also decreased in those with ME/CFS.

- Fibromyalgia patients require more time to successfully complete neuropsychologic tests as do polio survivors with fatigue.

- Like polio survivors, fibromyalgia patients have a decreased ability to make blood vessels contract, suggesting that they have damage to sympathetic nerves that control the veins as do polio survivors.

- Sleep apnea is seen in nearly half of those with fibromyalgia and in our post-polio patients.

- At least one-third of adults and children with fibromyalgia have sleep that is disturbed by involuntary leg movements such as those we have seen in polio survivors.

Given the overlap of symptoms in fibromyalgia and ME/CFS, the same non-polio enteroviruses might cause both conditions. Indeed, Danish virologist Irene Wittrup found antibodies to enteroviruses in 50% of patients with slow-onset FM, versus antibodies in 15% who reported symptoms occurring right after the flu. Our old enterovirus friend, Coxsackie B, as well as other viruses, have been linked to FM. And it is possible that baby-boomers may be misdiagnosed as having fibromyalgia, as they may be misdiagnosed with ME/CFS, when they actually had an undiagnosed case of polio and have PPS.

Kate: This is incredible. So what's the bottom line?

Dr. Bruno: Just like polio survivors, those with ME/CFS and FM have no more time to waste with doctors who don't "believe" their symptoms or who think pain and fatigue are "all in their heads." It is time that doctors start looking at the cause of chronic fatigue from the brain up -- instead of from the mind down -- so that adults and young people with PPS, ME/CFS and FM get help for their symptoms instead of being blamed for them.

Kate: But what about the doctors who routinely prescribe exercise and cognitive behavioral therapy to people with ME/CFS and FM?

Dr. Bruno: They should read the literature and not subscribe to the "pull yourself up by your bootstrap" school of ME/CFS. Research by Australian exercise physiologist Garry Scroop makes clear that doctors should not prescribe exercise for ME/CFS patients saying, "The exercise program really destroys these patients, it puts them to bed." In an address to the British House of Lords on April 16, 2002, ME/CFS patron the Countess of Mar stated "As Nero fiddled while Rome burned," on UK exercise and CBT proponent "fiddles the facts while people suffer and die." Again, there is no more time to waste on doctors who won’t listen, won’t read, won’t think and only "believe’ PPS, ME/CFS and FM "don't exist."

Even if you can't find a doctor to "believe" you or can't get to a competent specialist, you can take treatment into your own hands and start taking care of yourself right now. Ask your doctor for blood tests to rule out other conditions, especially anemia and a slow thyroid. Ask to have a sleep study. And start practicing energy conservation, work simplification, pacing activities, taking frequent rest breaks and living by "The Golden Rule."

Kate: "Evidence-based treatment" seems to be the Golden Rule of medicine and rehabilitation centres. Is there evidence that these "post-polio" management techniques REALLY work for ME/CFS and fibromyalgia?

Dr. Bruno: Here is Dr. Dowsett’s conclusion:

"There is very little, if any, difference between ME/CFS and PPS. In 1986, I started reading Dr. Bruno’s articles and have used them as guidelines for the management of my patients ever since. His treatment programme has amply proved its worth as some 300 Christmas cards from patients all over the UK and from around the world testify. I also have many letters from doctors who say that their patients have truly benefited."

Kate: Now that you've told us so much (thanks!), what more will Canadian patients and health professionals learn from attending the symposium on June 15?

Dr. Bruno: There will be plenty for everyone. Dr. Dowsett and I will discuss in detail everything we've been talking about here: the causes of PPS, ME/CFS and FM; the historical and physiological and clinical connections between them; and most importantly, what polio survivors and ME/CFS and FM patients can to do treat themselves. I'll even be signing my new book. Now is the time for everyone with chronic fatigue and pain to come to the aid of their own bodies and not just survive but thrive in spite of PPS, ME/CFS or FM.

Kate: Thanks very much for all of your research, clinical work and advocacy!

About Dr. Richard L. Bruno: Dr. Bruno is a clinical psychophysiologist specializing in the treatment of chronic conditions -- fatigue, pain, and stress -- as well as Post-Polio Sequelae. He is Chairperson of the International Post-Polio Task Force, an Associate Professor at New York's Mount Sinai School of Medicine, and Director of The Post-Polio Institute, the International Centre for Post-Polio Education and Research and the Fatigue Management Programs at New Jersey's Englewood Hospital and Medical Center. Dr. Bruno advises both the US Congress and federal government on post-polio issues and is an advisor and patron to PPS and ME/CFS groups on four continents.

Dr. Bruno is Director of Fatigue Management Programs and The Post-Polio Institute at Englewood (NJ) Hospital and Medical Center

"GETTING IT RIGHT FOR CANADIANS": A Government Response to Lobbying about the Disability Tax Credit by the CCD:

In its April 2002 issue of its newsletter, "Voice of Our Own', the **Council of Canadians with Disabilities** reported that, after receiving many complaints from consumers regarding the Disability Tax Credit, "CCD urged the House of Commons Sub-Committee on the Status of Persons with Disabilities to investigate the Canada Customs and Revenue Agency's administration of the Disability Tax Credit." After a 3 month investigation period the Sub-Committee released a report entitled, "Getting It Right For Canadians".

The report called for:

An apology by CCRA to the 106,000 Canadians who received a poorly explained letter from the Agency indicating that they were no longer eligible for the DTC despite the fact that these individuals have been receiving this credit for anywhere between six and seventeen years;

Compensation for the expenses of those who successfully re-certify;

No new reassessment of claimants until the certification is revised and new procedures and forms put in place;

Immediate amendments to the Income Tax Act, so that It incorporates recent court decisions;

Consultations with the disability community and medical professionals to draft amendments to the Income Tax Act that spell out exactly the eligibility criteria for the tax credit that reflect the reality of living with a disability;

Re-designing the Form T2201 that establishes eligibility for the tax credit and streamlining the approval process;

An educational campaign for the public, medical practitioners and tax preparers;

An evaluation of the Disability Tax Credit and a re-examination of all tax measures affecting persons with disabilities.

National ME/FM Action Network applauds the CCD for its advocacy. Council of Canadians with Disabilities 926-294 Portage Avenue Winnipeg, MB (Tel/TTY:204-947-0303)e-mail to ccd@pcs.mb.ca - http://www.pcs.mb.ca/~ccd/

MACLEANS' ARTICLE RESPONSES - Sick and So Very Tired - By: Danylo Hawaleshka - April 15, 2002

Response No. 1 from Lydia Neilson, President, CEO National ME/FM Action Network - April 17, 2002

Maclean's Letters

777 Bay St.

Toronto, ON M5W 1A7

Dear Editor:

On behalf of the National ME/FM Action Network, I would like to thank you for publishing the informative article by Danylo Hawaleshka on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in the April 15, 2002 issue. We would like readers of Maclean's to know that there is a national advocacy organization working on behalf of the many Canadians with ME/CFS and also Fibromyalgia. Interested people can contact us.

We are pleased that Maclean's highlighted the stories of patients who are severely disabled by ME/CFS as this situation is very common. It is tragic that disability claims have been denied to so many of them and that teenagers can be so profoundly afflicted. As you also pointed out, some people do appear to go into long-term remission or recovery. This demonstrates the importance of an early diagnosis and appropriate treatment. Our organization is working hard to educate so that the long-term outcomes of people with ME/CFS can be improved.

Once again, thank you for bringing this devasting illnes to the awareness of the Canadian public.

Response No. 2 – From Alison C. Bested, M.D., F.R.C.P (C)

CFS patients in my practice are encouraged to exercise, within their limitations, to improve muscle strength and prevent osteoporosis. Any activity, including exercise, must be paced so that the patient doesn't "crash" or end up in bed the following day(s). Resting before and after the activity allows the patient to do more and it promotes healing. Manon Houle, who maintains that "rest is useless," may not have read the literature review on CFS published in the Journal of Clinical Psychology (2001). In this paper, psychiatrist Fred Friedberg and psychologist Leonard Jason suggest that patients "schedule rest and relaxation intervals, even when less symptomatic." In 10 years of clinical experience treating CFS, I have found that this advice, when combined with activity pacing, leads to gradual improvement in functioning. Dr. Alison C. Bested, Toronto

[**Editor's Note:** Dr. Bested, a Haematological Pathologist, who has diagnosed and treated hundreds of patients with ME/CFS and/or FM, was one of the doctors chosen by Health Canada to peer-review the Canadian Clinical Definitions, Diagnostic and Treatment Protocols document for ME/CFS last March 2001, hosted by the **National ME/FM Action Network**. Dr. Bested co-authored a research paper on the blood/brain barrier and its possible connection to ME/CFS published in Medical Hypothesis 2001; See QUEST #49, August/September issue.]

THIRD-PARTY ASSESSMENTS MUST BE OBJECTIVE – By: Mary Ellen, Manager – Special Projects

Independent medical examiners writing reports on behalf of insurance companies or Canada Pension Plan (CPP) are required by their colleges to write scientifically-based reports that are objective and written in neutral language. Words such as "manipulative", "deceptive", "cunning", "malingering" have been seen to appear in some reports to describe patients. These words are not neutral. We are aware that the Colleges have been disciplining some health care practitioners who have used these words in reports. We urge you to complain to the appropriate regulatory bodies if you have been described in an IME report with language that is not objective or neutral. Please place a cc. **National ME/FM Action Network** at the bottom of your letter and mail us a copy so that the Colleges are aware that we are keeping track of the number of complaints.

The **National ME/FM Action Network** continues to collect data for our National Registry from people who have been asked to attend an IME or FAE by an insurance company, CPP or Workmen's Compensation Board. We are determined to work towards protecting human rights.

To receive a copy or copies of the simple, confidential, 7 question Registry Submission Form, please Contact: Mary Ellen, Manager of Special Projects, Phone or fax: (905) 831-4744

Mail: P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON., L1V 6P7

Email: **marye@pathcom.com** **Or download the Form from our website at www3.sympatico.ca/me-fm.action**

TEACH-ME: A Sourcebook for Teachers of Children With ME/CFS and/or FMS – Hard Copy Available Now - $22.00

By: Mary Ellen, Chairperson, TEACHo-ME Task Force

TEACH-ME offers information and educational principles to teachers who may have students with Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS) and/or Fibromyalgia Syndrome (FMS). The authors are Canadian teachers, disabled with ME/CFS and/or FMS, who are members of the **National ME/FM Action Network**. We developed a unique e-mail conference,

known as TEACH-ME, in which we discussed ways that children with ME/CFS and/or FMS could be provided with uninterrupted, high quality education. As people with ME/CFS and/or FMS ourselves we were devastated to imagine the effects of ME/CFS and/or FMS on young people.

We were very privileged to have the consultation of Dr. David S. Bell and Mary Z. Robinson. Dr. Bell is a renowned pediatrician and the leading researcher on ME/CFS and/or FMS in children. Ms. Robinson is a US educator, research assistant to Dr. Bell, co-author of "A Parent's Guide to CFIDS", and parent of two young people with ME/CFS and FMS. Our collaboration with Dr. Bell and Ms. Robinson enabled us to link our personal experience and teaching expertise with the most up-to-date and sound international research

knowledge. Not only that, but Dr. Bell's and Ms. Robinson's knowledge of ME/CFS and FMS is unique in that it has been acquired from following real families and children coping with this illness over many years. We are also greatly indebted and make much use of the pioneering work of many other researchers. The Sourcebook recommends educational policies and practices in keeping with the advice of international experts on the impact of these illnesses on children.

Since this issue of QUEST highlights the parallels between post-polio sequelae and ME/CFS and/or FMS, readers will be interested to know about research on youth with ME/CFS from that perspective.

In an interview for a parents' newsletter, Kate Andersen, asked Dr. Bruno about his research on children with ME/CFS?

Dr. Bruno: We did the first study of the psychophysiology of young people reporting chronic fatigue using the same techniques we used to test polio survivors with fatigue. We evaluated thirty-eight young people reporting fatigue and studied thirteen subjects, who were on average 16 years old and met the 1994 Centers for Disease Control diagnostic criteria for Chronic Fatigue Syndrome. We also studied 10 non-fatigued control subjects.

We gave 12 neuropsychologic tests of attention and did EEGs and found three things. First, 75% of the young people with CFS had no psychiatric diagnoses at all, not even an adjustment disorder with depressed mood. This finding disproved the notion that ME/CFS is a psychiatric disorder that could not and should not be diagnosed in children.

Second, subjects' reports of difficulty staying awake during the day and difficulty concentrating -- the same symptoms reported by adults with ME/CFS and polio survivors with fatigue -- uniquely predicted the diagnosis of CFS, and difficulty staying awake during the day, concentrating and focusing attention were significantly correlated with daily fatigue severity.

Third, scores on four of the neuropsychologic tests of attention were clinically abnormal in the CFS group, while scores on two additional tests of attention were statistically significantly lower in the CFS subjects and significantly correlated with daily fatigue severity. There was no difference in EEG between the two groups, probably because the age span of the subjects caused their differing basal EEG frequencies to obliterate changes related to ME/CFS.

So in terms of symptoms and impaired attention - signs of brain activating system damage - ME/CFS kids looked just like adults with ME/CFS and fatigued polio survivors.

Kate: So what is the treatment for children with ME/CFS?

Dr. Bruno: It's the same as for adults with post-polio fatigue and ME/CFS: "The Golden Rule - If anything causes fatigue, weakness or pain DON'T DO IT! (Or do much less of it.) Dr. Ramsay himself said, "The basic fundamental tenet of the management of a case of ME is REST with graduated activity well within the limitations which the disease imposes."

Parents and young people with ME/CFS and/or FMS also made important contributions by sharing their real experiences. This book has international applicability, with very little content that is specific to Canada. A parent reviewer and wife of a teacher wrote: "This wonderful book has been a blessing in understanding and assisting our child. I'm very much looking forward to seeing it published so other parents may be benefited as well."

ATTENTION PARENTS WITH ME/CFS OR FM CHILDREN

Kate Andersen, our Youth Consultant, is surveying parents of young people with ME/CFS and/or FM about their children's neurocognitive and learning problems. This is preliminary research to help us determine what educational reforms are needed and to assist appropriately qualified researchers in neuropsychology and related disciplines to identify research questions. If you are the parent of a young person with ME/CFS and/or FM (aged 0-18), please consider participating in this important preliminary study. Please **Contact Kate** at **(604) 855-3673** or at **canadianyouthmefm@yahoo.ca**

May 12 Special Issue on Children and Adolescents with ME/CFS - By: Mary Ellen, Manager – Special Projects

BDINews is a free electronic newsletter published by Behavioral-Developmental Initiatives in the United States. It has a wide professional and parent readership. The newsletter is a professional activity of **Kate Andersen** who is also the Youth Consultant, for the **National ME/FM Action Network**. Kate announces that the May 12, 2002, issue of BDINews will be focussed on children and adolescents with ME/CFS. It features a letter from a parent who reviewed the **National ME/FM Action Network's Sourcebook for Teachers**, an interview with **Dr. Richard L. Bruno** about his research on adolescents with ME/CFS, an article by US parent advocate, **Mary Robinson**, the school study of ME/CFS in England by **Dr. Elizabeth Dowsett** and **Jane Colby**, an article by a young person about communication between doctors and young people with ME/CFS and an informational article by Kate Andersen on ME/CFS in young people. Interested readers can request a copy of this free issue by emailing **bdinews@shaw.ca**

BOOKS/REPORT/VIDEOS ETC.

THE POLIO PARADOX: UNCOVERING THE HIDDEN HISTORY OF POLIO TO UNDERSTAND & TREAT "POST-POLIO SYNDROME" AND CHRONIC FATIGUE SYNDROME. [Warner Books, 2002] - By: Dr. Richard .L. Bruno

Signed copies will be available for purchase at the **First International Symposium on the Parallels between Post-Polio Sequelae (PPS), Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FMS) on June 15, 2002 hosted by the National ME/FM Action Network.**

Price: Canada $36.95 Cdn at H.B. Fenn. – To Order: Call Brigitte Viesti at 1-800-267-3366 or (905) 951-6600

Price: U.S.A. $25.95 U.S.at AOL Time Warner Book Group - To Order: Call Carol Meadows at (212) 522-8112

For International Orders, please contact: Bob Michel, AOL Time Warner Book Group at (212) 522-1778

CHRONIC FATIGUE SYNDROME: A Biological Approach - Editors: Patrick Englebienne and Kenny De Meirleir, Belgium

Price U.S. $99.95, 10% discount (U.S. $89.96) if paid by CreditCard.

To order: Call Marilyn DiPrima at: 1-800-272-7737 or (561) 361-6000 Ext. 6208 or mdiprima@crcpress.com

The book includes the many recent, biological discoveries that have helped give a better understanding of the physiology of this disease, and improve the specificity of its diagnosis by laboratory tests. It summarizes the most recent advances made in this field and discusses insights that support ME/CFS as a distinct and specific physical disease. The book includes advances in virology, bacteriology, immunology, protein chemistry and biochemistry, physiology and metabolism, clinical biology, pharmacology and epidemiology. It describes new insights and implications for the diagnosis and treatment. The authors are donating all royalties to research in ME/CFS.

[Ed. Note: K. De Meirleir, MD, PhD, is a member of the Canadian Expert Consensus Panel for the Canadian ME/CFS Clinical Definition Diagnostic & Treatment Protocols and attended the peer-review in Toronto in March 2001 hosted by the **National ME/FM Action Network**. He has treated approximately 5,000 ME/CFS patients, has approximately 300 scientific publications to his credit. Dr. De Meirleir is one of the foremost international researchers in ME/CFS and his research on the biochemical dysregulation of an antiviral defense pathway and the low molecular weight RNase L may lead to a blood marker for ME/CFS.

INTER-GROUP/CONTACT:

ANNOUNCEMENT: On Friday, **May 10**, **Kate Andersen**, Youth Consultant, will be representing the

National ME/FM Action Network on the **Bill Good Show**, CKNW radio, in Vancouver. MEBC Board member, Pat Woods, will be present. Also on the show will be **Dr. Bruce Carruthers**, well known British Columbia physician, medical advisor to MEBC, and one of the two doctors who drafted the Canadian ME/CFS and FM Clinical Definitions, Diagnostic and Treatment Protocols which was peer-reviewed last March 2001 when the **National ME/FM Action Network**, working in partnership with Health Canada, hosted the peer-review in Toronto, Ontario. On Sunday, May 12, Kate will be speaking on the **National ME/FM Action Network's** national vision of support for parents at a Mothers' Day Tea sponsored by MEBC. The tea is to honour mothers ill with ME/CFS and FMS or who have children with these illnesses.

Thank You **BARRIE & DISTRICT ME SUPPORT GROUP INC** and its President, **Albert Blom**. The **National ME/FM Action Network** appreciates your continued support of donating $1.00 per year for each member on your books.

Thanks YORK REGION CF/FM SUPPORT GROUP, Richmond Hill, Ontario for your generous donation towards our many projects.

Congratulations **Ted Purvis**, Pension Advisor, who helps many of our members receive their CPP Disability Benefits, on receiving the KAREN ANDERSON MEMORIAL CERTIFICATE OF RECOGNITION from the **Brockville M.E. Association** in recognition of his compassionate, caring attitude and respectful treatment of people living with ME/CFS and FM. Mr. Purvis can be reached at **(613) 269-4918**

OUR WORLD:

DEFINITION OF ME: Move over e-v-e-r-y-t-h-i-n-g!

DEFINITION OF FM: Frequent metamorphosis of ‘muscles’

"QUEST COLLECTION" BOOK - FIVE YEARS: By popular request, **the National ME/FM Action Network** has published an easy to read book consisting of a **collection** of important articles which have appeared in our **‘QUEST’** newsletters over the years. For easy reference, these articles have been grouped into sections, according to their focus i.e. medical, legal etc. We have kept the **cost** of the book to a minimum at **$20.00** each which includes shipping and printing. Please make **your cheque payable to the National ME/FM Action Network** and let us know how many copies you would like.

TEACH-ME - Sourcebook for Teachers. We are proud to announce that the hard-copy of **our Sourcebook for Teachers**, an educational resource book full of information and teaching strategies for teachers and parents of children and youth who have ME/CFS and/or FM.,is now available. Price $22.00 (includes S & H) – Discount on bulk orders. Cheques payable to the National ME/FM Action Network.. Please also see our youth and parents’ pages at: **http://www.geocities.com/canadianyouthmefm/teachme.html**

LEGAL/RESEARCH PACKAGE - **Medical** and **Legal** Information on ME/CFS and/or FM, a resource for lawyers, advocates, doctors and patients. Please make **cheque payable to Marj van de Sande** in the amount of **$25.00** (our Director of Education) to cover photocopying, postage charges etc., **151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 - Tel/Fax: (403) 547-8799 - E-mail:** vandesam@cadvision.com

MEMBERSHIP: **$25.00 per year which includes bi-monthly newsletters** – Please make cheque payable to: N**ATIONAL ME/FM ACTION NETWORK, 3836 Carling Ave., Nepean, ON K2K 2Y6 Canada – Tel/Fax: (613) 829-6667 –**

E-mail: ag922@ncf.ca **- Web: http://www3.sympatico.ca/me-fm.action/**

DISCLAIMER: The NATIONAL ME/FM ACTION NETWORK serves as a clearing house for information on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia. Some of the information contained herein is intended to help patients and their physicians make informed decisions about their health. However, the NATIONAL ME/FM ACTION NETWORK does not dispense medical advice or endorse any specific medical hypothesis or product and assumes no responsibility for any treatment or action undertaken by its readers.