

## Polio Particles 27

Mary Westbrook

### **Failure to vaccinate against polio means jail**

Under Belgian law polio vaccination is mandatory. The only other country that has taken this step is France, although Saudi Arabia demands that pilgrims to the yearly Hajj pilgrimage who come from countries in which polio is endemic must prove they have been vaccinated. They are also given another dose of vaccine when they arrive in Saudi Arabia 'just in case'. The *British Medical Journal* reported in February 2008 that two sets of Belgian parents who refused to have their children vaccinated against polio had been fined the equivalent of just under \$A9000 and sentenced to five months imprisonment. The sentence was suspended while parents were given a second chance to vaccinate their children. These events received much publicity around the world. Privacy laws in Belgium prevent publication of details about cases so it is not known how much time the parents were granted or why they refused to vaccinate. I have not found any reports on what the final outcome has been. Belgian law allows for an exemption to vaccination if it can be proved that the child would be adversely affected. The case attracted attention from bioethicists. Associated Press (12/3/08) quoted Professor John Harris, University of Manchester, as saying: *Nobody has a right to unfettered liberty, and people do not have the right to endanger their kids. The parents in this case do not have any rights they can appeal to. They have obligations they are not fulfilling.* Dr Ross Upshur, University of Toronto, said: *It's a pretty extraordinary case. The Belgians have the right to take some action against the parents, given the seriousness of polio, but the question is, is a prison sentence disproportionate?*

### **Getting up from a chair.**

The Winter 2008 issue of Post-Polio Health International's newsletter contained an informative letter from Clara Reiss, who needs to use her arms to get up from a chair. Recently when two physiotherapists saw Clara getting up *with my hand placed on the chair arms so that my fingers pointed toward my body, my elbows away from my torso they screamed together "Don't do that!"* as it could tear her rotator cuff muscles. They instructed her *to place my hands on chair arms in the opposite way, with my fingers pointing out, away from my body, leaving my elbows close to my torso.* Within a month shoulder pain that had been troubling Clara had disappeared. The newsletter obtained the views of several physiotherapists who agreed that the way suggested is better but Robbie Leonard pointed out that some survivors who *use unusual positioning for performing functional techniques do so because they are using the muscles that they have.*

### **Cognitive fatigue in polio survivors**

At the American Neurological Association's Conference in October 2007 Dr Olavo Vasconcelos and colleagues presented the results of a research study into *cognitive fatigue in survivors of paralytic poliomyelitis.* The researchers used computerised tests to investigate the effects of fatigue on polio survivors' mental functioning. Survivors who participated did not show any signs of diminished mental functioning when well rested. During the investigation the survivors were given a set of tests known as the ANAM (Automated Neuropsychological Assessment Metric). After an hour's break they were given the tests a second time. Most people improve on a second attempt at these tests due to having had previous practice but the scores of more than half of the polio survivors

decreased. Analysis of the survivors' actual answers indicated that the decrease in their scores was not due to a decline in survivors' accuracy but to increased reaction times as a result of fatigue.

### **Search for disabled models**

According to *The Guardian* (5/3/08), the BBC is planning a five part TV series with the working title of *Britain's Missing Top Model* in which *eight women with disabilities compete over three weeks to prove to a panel of industry experts that they have what it takes to be a mainstream fashion model...* "Our intention is to empower both the women featured in the project and thousands of others, who shouldn't be invisible to the fashion industry, just because they are disabled people" says director Richard Mc Kerrow. The series will follow the chosen women as they move into a London apartment together and are trained in every aspect of modelling from posing for photoshoots to location work and catwalks. The BBC, which is receiving support from disability organisations, is searching for women with disabilities, aged between 18 and 30, to participate.

### **Link between pain and fatigue**

Chronic pain and fatigue often coexist. *As many as 76% of people with chronic, widespread musculoskeletal pain report fatigue; and as many as 94% of people with chronic fatigue syndromes report muscle pain* according to Dr Lynn Burnes and colleagues, in an article published in the April, 2008 issue of the *American Journal of Physiology*. Women make up the majority of patients with conditions involving pain and fatigue eg chronic fatigue syndrome and fibromyalgia. Burnes' team have demonstrated a biological link between pain and fatigue which may help explain why more women have these conditions. The team, bred mice that were high or low levels of ASIC3 (an acid-sensing ion channel present in muscle) which is involved in musculoskeletal pain. They then compared the fatigue following exercise of groups of male and female mice who had high or low ASIC3. Various groups of mice did tasks such as three one-hour runs. The researchers then tested the mice's fatigue by measuring their temporary loss of muscle strength. One of their complex findings was that high ASIC3 male mice showed less fatigue than high ASIC3 female mice after completing the runs. However when high ASIC3 female mice were given testosterone, their muscles became as resistant to fatigue as those of the high ASIC3 male group. However low ASIC3 female mice's fatigue level were not helped by testosterone. The researchers concluded that there is *an overlap between fatigue and pain such that fatigue plays a significant role in the development of pain and pain is enhanced in response to fatigue*. In an interview with *Science Daily* (9/4/08) the researchers said: *The differences in fatigue between males and females depend on both the presence of testosterone and the activation of ASIC3 channels which suggests that they are interacting somehow to protect against fatigue. These differences may help explain some of the underlying differences we see in chronic pain conditions that include fatigue with respect to the preponderance of women over men...Our long term goal is to come up with better treatments for chronic, widespread musculoskeletal pain. But the fatigue that is typically associated with chronic, widespread pain is also a big clinical problem—it leaves people unable to work or engage in social activities. If we could find a way to reduce fatigue, we could really improve the quality of life for these patients.* I speculate about whether the findings will have relevance to post-polio syndrome which surveys show is more prevalent among women than men. This difference has sometimes been attributed to social factors such as women being more

likely to admit to health problems, join support groups, take part in surveys etc. In other words, the implication is that the surveys are not picking up many unidentified male cases in the community. While there may be some truth in this it might turn out that women polio survivors are more prone to some of the symptoms of PPS or experience them more severely.

### **Historic polio-free achievement in Somalia**

Polio was eradicated in Somalia in 2002 but the country became reinfected in 2005 when the virus travelled from Nigeria and 228 Somalian cases occurred. On March 25<sup>th</sup> 2008 Somalia was once again declared polio-free as there had been no cases in the previous year. This success was due to the over 10,000 volunteers and health workers. They immunised more than 1.8 million children under five years of age in what has been described by Rotary International, which contributed \$US9.2 million to the Somalian campaign, as *one of the most dangerous countries on earth*. One of the volunteers was Ali Mao Moallim, the last person to contract smallpox before it was eliminated from the planet in 1977. He said that *Somalia was the last country with smallpox. I wanted to help ensure that we would not be the last place with polio too*. Dr Costales a senior advisor with UNICEF said, *Somalia beat polio in the midst of more widespread conflict and poverty than that affecting Afghanistan and Pakistan...Somalia shows that when communities are engaged, children everywhere can be reached*.(Information from a Rotary International press release 31/3/08)

### **Not walking**

Professor Lisa Iezzoni of the Harvard Medical School, has MS and uses an electric scooter/wheelchair. She has written *When Walking Fails* (Published by University of California Press, 2003), a book about the effects of mobility problems. Several points in this interesting book of over 350 pages particularly caught my attention. She discusses how we are affected by society's views that walking connotes *independence, autonomy, perseverance, strength, achievement—'standing on your own two feet', 'walking tall', 'standing up for yourself', 'taking things in your stride'*. Conversely *societal views of walking problems remain a complex tangle of fears, discomforts, sorrows, rages and uncertainties* which make the notion of needing a wheelchair terrifying. *The phrases 'wheelchair bound' or 'confined to a wheelchair' imply that a wheelchair restricts the individual, holds a person prisoner*. In reality a wheelchair is a tool, the use of which enhances quality of life. Social attitudes toward walking also influence doctors. Iezzoni considers doctors often keep patients struggling with ambulation, insisting they must 'use it or lose it'. *For many people with progressive chronic conditions, however, this belief isolates the legs from the whole person. It assumes that the primary objective is to maximize failing muscle function rather than consider the totality of a person's daily life. Those who look beyond physical functioning believe it is ultimately more important and cost-effective to improve a person's quality of life*. She discusses Eleanor a polio survivor who was having so many severely damaging falls she *fought* with her doctors to get a wheelchair. Eleanor said that doctors *felt if I started using the chair I would lose more muscle in my legs. That wasn't the case because I don't sit in a wheelchair all day*. Eleanor walks around in her office and at home. For her as for many polio survivors a wheelchair is not an all or nothing option.

Like many survivors I've gone through the 'getting a scooter/ crutches/ a wheelchair makes this the worst day of my life' feelings. Advantages I noticed immediately when I began using a wheelchair was that being in a queue was no longer excruciatingly exhausting, it was no longer a terrible hassle if I left something in another room and had to go and get it, I could easily move round and talk to people when I went to an event such as a Network seminar, I could carry lots of stuff around including grandchildren (all impossible on crutches), I was much better humoured as I wasn't so tired, and shopping was fun once again. The world isn't surfaced in flat concrete so of course wheelchair travel is not always trouble free. As Iezzoni says, she *desperately wished to walk, but since I couldn't go far I decided to roll. Now I do and it's terrific! In a real sense, this book is a paeon to my wheelchair. She quotes journalist John Hockenberry, a paraplegic from spinal injury. In his autobiography, Moving Violations, John wrote: It took years of being in a wheelchair before I could be truly amazed by what it could do, and what I could do with it. On a winter night in Chicago, after a light snow, I rolled across a clean stretch of pavement and felt the smooth frictionless glide of the icy surface. I made a tight turn and...I saw two beautiful lines etched in the snow. They began as parallel and curved, then they crossed in an effortless knot....My chair had made those lines. The knot was the signature of every turn I had ever made...It was the first time I dared to believe that a wheelchair could make something, or even be associated with something, so beautiful.* Well, I have not encountered any light snow in Sydney but I find I get a great buzz gliding in my wheelchair, past everyone, down the slopes of a shopping mall. I haven't moved so fast since polio caught me aged eleven. I can almost feel the wind in my hair.