

POLIO PARTICLES 14

Mary Westbrook

Bone density tests for polio survivors

The May 2003 issue of the Rancho Los Amigos Post-Polio Support Group Newsletter reported a question and answer session that followed a talk by Dr Carol Vandenaeker, director of the Post-Polio Clinic, Department of Physical Medicine and Rehabilitation, University of California, Davis. She was asked: *'When you do a bone density test for osteoporosis, do you do a specific limb?'* She replied: *'We have started a study comparing a polio limb with a non-polio limb. There is a huge difference. What you want to be aware of is if your doctor just wants to know your over-all bone density they should not test a polio affected limb by itself. It will come out severely osteoporotic, and the rest of your limbs might be just fine. If you test a polio limb then it is important that they test your more normal limb as well.'* My experience was that I was asked which was my worst hip and the radiographer then proceeded to do a scan of my left hip and an area of the spine. I insisted that she also do the right hip and after some fuss she did. The left hip was very osteoporotic but on the other sites the bone density was good.

Iraqi stores of polio virus stolen

The *New York Times* (20/4/03) reported that on what they described as *bad Friday in Baghdad*. *On the Islamic holyday, thousands of Iraqis marched through downtown, shouting for America to 'leave our country'. Looters, continuing their rampage, stole vials of polio virus from a public health laboratory and set the Information Ministry of fire.* Nothing more was said in the article about the polio virus, and I can find no other reference to it on the web, so one can only speculate. Why was the virus being stored and what did the looters do with it?

Polio kick

Canadian, Dianne Hicks Morrow, has published a book of poetry titled *Long Reach Home* (Acorn Press, 2002). One section of the book, *Polio Kick*, contains ten poems about Dianne's life with polio. In the first poem she describes her mother asking:

*'You're not going to write another poem
about polio are you? One was all right,
but you don't want people to think you're fixated'
Breathe stops. Heart pounds.
We keep swimming. At last I say,
'I don't care what anyone thinks'
After forty-seven years of holding my breath, it's
Time.
I am on a polio kick.*

One poem describes the photo of Dianne taken when she was seven months old, the day she developed polio. In the poem her mother says:

*I sent the door-to-door photographer away,
Then called him back in case you were so sick you died.*

In *Mirror* Dianne asks

'You mean if I have surgery my skinny leg will look like my big one, Mommy?'

'Well no dear. You'll be able to walk better'.

As her mother shows her, in front of a mirror, how to lift her foot when walking Dianne realises she is different

I've seen people who walked like that.

I didn't know I was one of them.

Difference is a theme of many of the poems. The boy she has a crush on

He confessed he always thought

I was great but he couldn't ask me out

because of my '(uh) limp, I know it isn't right,

but I just can't handle (uh), you know

deformity'.

In the era of miniskirts she dreamt of wearing long skirts. She was born *too early for the blue jean craze/ that would make her look like everyone else*. The author writes of envying *other legs / --fat ones, skinny ones, bowed ones--/ they match*. Alas *her traitor ankle can turn, / drop me without warning, / force me to admit/ I am unbalanced*. I wished some poems had spoken of post-polio issues. In the acknowledgements Dianne refers to an editor whose advice to *'write about what haunts you' allowed me to look at the unspoken theme of disability in my family*. Some of the poems are about her mother's visual impairment. Of added interest to me was that the author lives on Prince Edward Island and though *Anne of Green Gables* is not mentioned there are references to places and landscapes I first read about in the Anne books.

Polio Eradication strategy revised

In its *Science Update* (16/5/03) the journal *Nature* reported that WHO has just launched a revised polio eradication program because of lack of financial resources. This could be the undoing of the campaign warned its coordinator, Bruce Aylward, who says an extra \$US275 million is needed. In the revised program *51 intensive immunization campaigns will target 13 polio hotspots...the new tactic re-routes dwindling funds, which previously ploughed into another 80 countries to areas where polio is rife or where people are deemed 'at risk' from re-infection from neighbouring countries*. According to *Nature* some experts warn that *the total eradication of polio is an unrealistic goal....One problem is that even in areas now free of polio, long-term vaccination is needed to protect against the occasional immunized individuals who carry and spread the disease. One man in Britain has excreted high levels of poliovirus for 20 years (see Newsletter 56); indeed 14 carriers have been found by chance since 1988. What's more, the live, weakened form of poliovirus used for vaccination can mutate into a more aggressive, disease causing form. This can be a problem in areas where vaccination levels are low and the virus can gain a foothold. In 2000, more than ten vaccine derived polio cases were reported in the Dominican Republic and Haiti. This is further evidence, says Henderson, that 'we need to plan to provide the vaccine indefinitely*. (Dr Henderson led WHO's successful eradication of smallpox).

Being a parent with polio

Many of us who had children after we contracted polio met with some social disapproval. *How can you manage to look after a baby properly?* We worried ourselves at times whether our children were disadvantaged by our disability. So it was heartening to read in the *Australian's* column *The Making of Me* (17/5/03) that Caro Llewellyn, director of the Sydney Writers' Festival, puts her father at the top of the list of important influences in her life. She said: *A disabled father. My father is in a wheelchair and I think his attitude has had a profound effect on me. He's led such a full life—he's 65 and still working, which has inspired me to make the most of life. I had never heard him complain that he couldn't play with us or be a dad in the traditional sense until one day as an adult, we were watching my little brother and sister playing cricket on the beach and Dad said to me, 'It's times like this I wish I wasn't sitting in this chair'. As a child Dad had woken up one morning and couldn't move. He had polio. Growing up knowing this I don't take anything for granted.* JoAnn le Maistre who has MS wrote that she has come to realise that parents with a disability *may give our children something that is uniquely the result of our physical disabilities. If we are self-accepting our children will learn not to be afraid of disabled people, will admire and wish to emulate the strength of our daily struggle, and will accept for an entire lifetime the simple, but too often hidden fact, that there are no perfect people, no perfect lives.*

Some years ago Dr Darien Chinnery and I carried out research comparing the pregnancies and early childrearing experiences of able-bodied mothers with those of mothers who had a mobility disability (Australian Disability Review, 1995, no.3). We found that women with disabilities were much more likely to encounter negative reactions to their pregnancies (including pressure to have an abortion) and were less likely to receive help from their relatives after the birth of their babies. The satisfactions and problems of childrearing encountered by the two groups of mothers were very similar. We concluded that negative social attitudes toward physically disabled women having children create an additional handicap for them.

National influences on polio outcomes

Differences in social attitudes, social conditions and healthcare make some countries a better place to contract polio. A research study by T. Rekan and others (published in the *Journal of Epidemiology and Community Health*, May, 2003) examined the long term outcomes for polio survivors in an eastern and in a western European country. They compared patients who were hospitalised with polio in the 1950s in Norway and Estonia. The medical records of the 148 Norwegians and 128 Estonians were examined and survivors were interviewed. Despite the fact that the Norwegians had more severe disabilities in the acute stage of polio they were significantly more likely than the Estonians to be working (both full or part time) in 1998, the year of the study. The Norwegians were also more likely to have worked in the preceding 40 years. This finding was unexpected as disability pensions are more readily available in Norway. In both countries 30% of the survivors had done manual work and 18% had changed their type of work during their careers. Survivors' incomes were evaluated in terms of their national average. Having a low income (less than 50% of the national average) was reported by 73% of Estonians and 35% of Norwegian survivors. The late effects of polio reported by the two national groups were similar except that Norwegians reported more muscle pain.

Norwegians were more likely to exercise regularly. Use of assistive devices was similar for the two groups. However Norwegians were more independent and less likely to need assistance with housekeeping. The authors concluded that there are advantages of living in a country with more social, economics and medical resources such as availability of ongoing rehabilitation e.g. physiotherapy, They point out that today the largest and youngest populations of polio survivors are living in countries with few such resources. I recently read of a rehabilitation program for amputees and polio survivors in Afghanistan which gives them mobility by training them to ride a bike. I couldn't help thinking of all the polio survivors who would not have the muscle strength necessary to succeed in such a program and who remain isolated at home.

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