

## Polio Particles 30

Mary Westbrook

### **Effective resting**

*Rancho Los Amigos Post-Polio Support Group Newsletter* June 2009 reported a talk given to the group by post-polio specialist, Dr Vance Eberly. In the course of his talk he discussed the overuse of post-polio syndrome muscles that causes muscle pain and twitching. He said that resting is very important both as a preventive measure and when you are suffering the effects of overdoing and emphasised the importance of lying down to rest. Dr Eberly stated that, "Many people need to break up their day; they lie down for 15 or 20 minutes, two or three times a day. That helps especially with back pain. Post-polio syndrome frequently affects your spinal muscles and your anti-gravity muscles. So sitting down doesn't help because you are using those muscles to sit upright. If you didn't use them you would flop over. Polio survivors need to get out of the chair and lie down to rest those muscles."

### **Research into polio virus fragments in polio survivors**

Each year the Research Fund of Post-Polio Health International (PHI) in St Louis makes an award. The 2008 award of \$US25,000 was given to a group of researchers at the University of Insubria Medical Centre, Varese, Italy headed by Antonio Toniolo, Professor of Microbiology and Virology. The grant will fund a study *Persisting Noninfectious Fragments of Poliovirus in PPS patients: Virus Detection and Susceptibility to Antiviral Drugs*.

Past research has detected fragments of poliovirus in the cerebrospinal fluid of PPS patients. It is speculated that these may trigger a chronic inflammatory response in the body which may be responsible for PPS symptoms. If this is so an antiviral treatment may be possible. Toniolo and his team plan to investigate the genetic structure of the persistent poliovirus fragments found in people with PPS and compare them to wild-type polioviruses. They will then test the susceptibility of the fragments to antiviral drugs. The board president of PHI, Lawrence Becker, said that the research team impressed PHI "as having real promise for tracking down the etiology of post polio syndrome. And if it turns out that these viral fragments play a major causative role, the study will not only help develop an important diagnostic tool, but may point the way toward an effective treatment." This could benefit many people because as PHI points out there are over 20 million polio survivors worldwide and PPS is the world's most prevalent motor disease.

### **Finding words to describe symptoms like fatigue**

Polio survivors often say that that they find it hard to explain to others what the fatigue they experience feels like; that it isn't just the same as what able-bodied people describe as feeling tired and furthermore fatigue comes in various forms. Are we right? Some support for the existence of distinct types of fatigue comes from a study comparing the way people with chronic fatigue syndrome (CFS) and the people in the general population perceive pain. This is relevant to polio survivors as a number of researchers have described the fatigue of CFS as similar to that of PPS and some have speculated that CFS is caused by a virus of a similar type to the poliovirus. The study was conducted by Leonard Jason and a team of researchers who reported their findings in *Disability Studies Quarterly*, 2009.

Using a questionnaire they developed the researchers found that people with CFS distinguished five types of fatigue. These were: 1) Post-exertional fatigue exemplified by statements such as you feel physically drained after mild activity, and minimum exercise makes you tired, 2) Wired fatigue eg it's hard to sleep because you are

tense and agitated, your body feels overstimulated when very tired, 3) Brain-fog fatigue eg thinking is hard work and muddy, you misplace items and cannot remember things, 4) Energy fatigue eg you do not have energy to do anything, you lack the energy to talk to anyone, 5) Flu-like fatigue eg you have muscle aches or pain all over your body, you feel like you have a high temperature or fever. In contrast the able-bodied participants' view of fatigue was that there is only one generalised type of fatigue, primarily a feeling of drowsiness or tiredness which may be accompanied by some of the symptoms the CFS group described but these were not experienced as separate types of fatigue.

My hunch is that polio survivors would make somewhat similar distinctions. The researchers consider that understanding the distinct types of fatigue patients may be experiencing will help health practitioners provide individualised treatment options. Understanding types of fatigue will help patients communicate with their family, friends and health-care providers. I remember that reading the distinction Dr Lauro Halstead made between various types of post-polio pain was a liberating experience for me because I now had a vocabulary to communicate with health professionals and family. Halstead distinguished three types of polio pain. He described type I pain as post-polio muscle pain which "is felt only in muscles affected by polio. It can occur both as a superficial burning discomfort or as a deep muscle ache...the deep pain is often characterised by muscle cramps, while the superficial pain is sometimes associated with fasciculations (twitching), a crawling sensation, or extreme sensitivity to touch" (*Managing Post-Polio; A guide to living well with post-polio syndrome*, page 38). At its worst I find this crawling pain almost unbearable yet none of the pain vocabulary I had learnt seemed to justify calling it pain until I read Halstead. [The second edition of Halstead's book is available from the Network office].

### **Polio elders**

*Living with polio in the 21<sup>st</sup> century* was title of the 10<sup>th</sup> Post-Polio Health International Conference which was held in Warm Springs this year. Sunny Roller, a polio survivor and researcher, gave a talk on her research into polio elders' life experiences of coping with polio. Elders were selected as being highly regarded role models within their PPS support groups in the USA. All were over 65 and more than 50 years past the onset of their disability. From her interviews with elders Roller found that:

- Major issues throughout these polio survivors' lives included: "Achieving and maintaining independence which requires diligent effort; fighting shame and creating a positive self-image with a disability; and reconciling social and functional losses."
- Elders' perception of being disabled from polio had altered over the years. "The years with polio during childhood, adolescence and as an adult were not comfortable....Before developing PPS in mid-life elders had worked hard using their 'lens of difference', a self-perception that rejected the shame and prevalent social stigma of disability. High achievement was crucial. Later in life they became more willing to look at their lives through the 'lens of disability', more fully embracing their disability as part of their overall personal identity. In doing so they became more content with this new self-perception and life in their retirement years."
- The main coping strategies survivors had used were "having a strong social support system, enjoying life, being optimistic, self-acceptance, assertiveness, education and spirituality."

"Ironically", Roller comments, "growing older with greater disability has offered this group a fresh sense of not only comfort, but also liberation....Once retired, there was no longer, a need to prove oneself in the mainstream workplace and keep up with

non-disabled competitors....In many important ways, life was reported as better in old age than it ever was in youth.”

Roller also commented on the wisdom of the polio elders but noted that “this group’s strong suit was not necessarily sympathetic and compassionate love for others. It may be that for this group, because of their life experience with disability, survival skills often had to trump compassion. Early on they learned that they had to work through the pain they may have felt physically through the years and rise above it. They had no time to feel sorry for themselves if they wanted to make it in society....Rehabilitation professionals and parents were tough on kids with polio because they were seen as having much weakness to overcome. Hence this study’s subjects warned others about not associating with negative people too much. They would drag them down. Because they had to go beyond their own self-pity to overcome disability, they did not approve of self-pity in others and expressed low tolerance of ‘whiners’. As one participant said, life with polio could make a person ‘damn tough’.”

### **No time for tears**

Roller’s comments on the historical reasons for the polio elders’ lack of compassion came to mind when reading *Bracing accounts: The literature and culture of polio in postwar America*, a book by Jacqueline Foertsch (published by Fairleigh Dickinson University Press, 2008). Various sections of the book discuss what women’s magazines wrote about polio (titled, “A battle of silence”), what novels covered (titled, “Crippled by history”) and what memoirs reported (called, “No time for tears”). *No time for tears* was also the title of Charles Andrew’s 1951 book about his ten-year old son Chuck’s attack of polio. Foertsch writes, “When finally allowed to visit [the hospital], Chuck’s parents cheerfully invalidate his fear and sadness”. Later when Chuck learns he may not be home for Christmas his father wrote, “He screwed up his face and began to cry...We remained immobile until he got under control”. Foertsch commented that Andrews attributes Chuck’s near-total recovery to his “blustering philosophies about ‘ignoring handicaps’... while in fact Chuck may have done as well as he did despite his parents’ emotional coldness and misguided doctoring”. Many other memoirs Foertsch describes and many Network members’ personal stories of their hospitalisation contain such incidents of ignoring or punishing children’s distress.

Roller suggests that the wisest of the polio elders she studied (see previous article) were “the ones who revealed that their experience with disability is now, in later life, making them more compassionate toward others with a disability, because they have grown in greater self-acceptance with their own disability”

### **Polio survivor returns to India**

Gautam Lewis was born in India in 1977. He contracted polio when he was 3 years old and was abandoned by his mother at Mother Teresa’s orphanage in Calcutta. Here he met a young British volunteer, Patricia Lewis, who adopted him when he was 7. In England he attended exclusive schools; Hill House with Price William, and Bedales. “It is ironic that I came from the poorest of poor families in Bengal and ended up studying with the richest children in England”, Gautam said. Following university Gautam has had a career in the music industry managing bands, run an events company and set up *Freedom in the Air*, a flying school for disabled people in the UK. Gautam is now an ambassador for *Rotary International* and for *Global Polio Eradication Initiative*. Gautam, who uses crutches, regularly returns India to take part in the polio eradication campaign. A 25 minute film of his experiences, *Passport to Polio*, was recently shown on Al Jazeera TV and may be viewed at their website (in English) <http://www.freedomintheair.org/?p=1545> The film follows his emotional visit

to the orphanage in Calcutta where he was abandoned and a treatment centre for children with polio. In an interview with *Ouch*, the BBC disability program (9/4/09), Gautam said he had not wanted to revisit his past “because it was an unstable childhood full of heartache, in a place which provides life and not much else... I was lucky to survive [polio] in a time and place when 1 in 5 children were dying of it. Part of me thinks it’s brilliant that I had polio, because without it the rest of my life wouldn’t have happened. But I’ve had to work hard to be fit and, above all, independent”. I recommend the film which besides giving insights into the frontline of the battle against polio today also has scenes of the treatment of polio reminiscent of our past. Remember having plaster splints made?

### ***Polio Free Certified stickers***

The National Highways and Motorways Police in Pakistan have launched a *Polio Free Certified* car sticker campaign in collaboration with UNICEF and other agencies involved in polio eradication. It is hoped that this initiative will result in children in transit during polio immunisation rounds being identified and vaccinated. A polio vaccination facility information has also been made available via the toll free emergency helpline (Reported in *The News from Islamabad*, 21/11/08).

### ***New medical assistive device?***

An American company has produced the *Palm Pistol*, a gun for disabled people “who may have limited strength or manual dexterity. Using the thumb instead of the index finger for firing, it significantly reduces muzzle drift, one of the principal causes of inaccurate targeting”. The company is trying, so far unsuccessfully, to have the gun marketed as a medical device for which the US government will reimburse seniors who buy the \$US300 firearm. The manufacturer says that it’s something people with arthritis and other disabilities “need to assist them with daily living...no more or less than for a walking aid or wheelchair”. Only in America! (Story from *New Scientist Tech* 16/12/08).