

## POLIO PARTICLES 19

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### **Queensland research into polio survivors**

An article, *The late effects of poliomyelitis in Queensland*, by physiotherapists Mary Lynch and Nancy Low Choy was published in the June 2004 issue of *Australasian Epidemiologist*. It reported a questionnaire survey of 126 survivors who were recruited from the waiting list of a Brisbane Post Polio Clinic (no longer operating). The most common new symptoms experienced by polio survivors were new muscle weakness (87%), unusual tiredness (79%), joint pain (79%), cramps (71%), walking changes (69%), muscle pain (61%), and increased falls (60%). The main activities of daily living which survivors needed increased assistance with were heavy household tasks (46%), climbing stairs (42%), and using public transport (37%). Changes to their employment (eg working fewer hours) had been made by 67% of respondents who were still working. Almost all survivors (83%) reported having made lifestyle changes as a result of their symptoms.

### **Expert patients and doctors**

As very few health practitioners are well informed about the late effects of polio, most polio survivors have had experiences of having more knowledge about some aspects of their condition than do the practitioners they consult. Some practitioners value their patients' knowledge and are keen to learn more about PPS. Other practitioners ignore or angrily dismiss our knowledge. The editorial in a recent issue of the *British Medical Journal* (27/3/04) carried the headline, 'Expert patient—dream of nightmare?' It said that when *doctors come across the term 'expert patient' they hear different things*, ranging from doctors who regard expert patients as *people who have the confidence, skills information and knowledge to play a central role in the management of life with chronic diseases* to those whose *expert patient of the imagination is one clutching a sheaf of printouts from the internet, demanding a particular treatment that is unproved, manifestly unsuitable, astronomically expensive, or all three. Or possibly worst of all, a treatment the doctor has never heard of.* The BMJ comments: *If one asks lawyers, architects, social workers, or management consultants whether they prefer clients who take an interest in the issues they face and are motivated to work in partnership to achieve successful results, the answer seems obvious. So why does the idea of expert patients provoke such antipathy within the medical profession?* The Chief Medical Officer for England is currently promoting the idea of the person with chronic illness becoming an expert or knowledgeable patient. Surveys show that most British doctors dislike this promotion; 63% saying expert patients will take up more of their time. In fact, says the BMJ editorial, research studies show that expert patients make less visits and better use of visits to doctors and manage their symptoms better. In any case, says the editorial, *all patients with chronic conditions and their carers are experts regardless of how much medical knowledge they may have....As highly educated professionals in well paid employment, doctors are not necessarily best placed to understand the realities of life for many of their patients, particularly those living with debilitating medical conditions, who are disproportionately unemployed, old and poor..* The editorial concludes: *Long live expert patients—but in the interests of doctor-patient relations, let us find something else to call them. What we need is a simple, understandable phrase that is less prone to evoke hostility. For our money the best term is 'involved'...involvement clearly requires at least two parties, rather than implying that the health professional role is somehow redundant ...Neither intimidating or patronising, involvement is a broad church in which many if not most of us would be happy to find a home.*

### **'End of polio' exhibition**

The Griffin Museum of Photography near Boston recently presented this exhibition by Brazilian photojournalist Sebastiao Salgado. One reviewer (Milford Daily News 29/8/04) wrote that Salgado *documents the suffering and hopes of humans ravaged by polio with unforgiving realism. An 11-*

year-old polio-stricken child, wearing sandals on his knees for protection, crawls into a soccer game in Somalia. A father pours a vial of vaccine into his son's mouth in a railroad car in India where they've been confined to prevent the disease's spread...[the museum director says] Salgado's photos 'go far beyond promoting public awareness of a cause. They grab you and force you to face the pain of others with the hope that you will be motivated to fight for change'. Many of the photographs can be viewed on [www.endofpolio.org/home.html](http://www.endofpolio.org/home.html). Large posters of some of Salgado's photos will soon be on display at Westmead Hospital. His photographs will also be shown at a Rotary exhibition on polio to be held at the Australian National Museum in Canberra from December to February, 2005. The Managing Director of Aventis Pasteur, which will be a major sponsor of the Rotary exhibition has presented the Network has a book of Salgado's photographs.

### **Rhonda Galbally and polio**

Rhonda Galbally AO has recently written her autobiography, *Just Passions*, published this year by Pluto Press. Rhonda was CEO of VicHealth and has started a company, *Our Community*, to support and advocate for community groups. Rhonda contracted polio when she was 13 months old and spent much of her childhood in hospital having surgery. Her family *all hated my disability. We saw it as the worst thing that could happen to a family...I would have given any thing, promised anything, for the miracle of complete recovery..* Her parents resisted health practitioners' pressure to place her in a school for crippled children. Some children, she writes, *were not so fortunate. Their parents would choose full-time medicine over full-time education...By focusing on physical gains, these children would end up as adults with little education, often having to take jobs in sheltered workshops (some of which are sweatshops) or having no job at all.* As an adult Rhonda confesses to an awful secret -- *I shared other people's loathing of disability. Until I joined the disability rights movement I didn't recognise my own hatred of disability—it had been repressed...I was leading a split life. I demonstrated in front of the Miss Australia Quest, a beauty contest run by the Spastic Society on behalf of disabled inmates who were never going to win...At the same time I would still have done anything to avoid being thought of as really disabled. So I refused to use a wheelchair at airports, even though I'd nearly pass out from pain and exhaustion as I struggled down the concourse.* The late effects of polio led to Rhonda in turn adopting walking stick(s), crutches, scooter and wheelchair. *Paradoxically, the more I use equipment the more disabled I look to others, but the more mobile I am. I tried to explain this to my mum, who took months to agree to go walking with me in my chair. It's not a failure, I told her...it's a symbol of flexibility and success in finally coming to terms with my disability.* Rhonda says her first childhood experience of technology was as a sadistic tool of mainstream medicine. One evening with a friend, who has cerebral palsy, *The grog loosened up our memories and took the edge off them, making them bearable to recall and even tell one another. It also loosened our sense of humour. We shrieked with laughter (with a strong edge of hysteria), as we tried to imagine the mentality of the person who made up instruments of torture to stretch little babies; he must be called Thomas, because the main weapon was the double-Thomas splint, a rack where little children were spread-eagled on a crucifix with parted legs and tied in with bandages so they could move only their hands. Your feet were bandaged into plaster boots, and a strap drew out your knees...Your hands were set into beautiful beaten stainless steel, to prevent them going out of shape. And you just lay on a bed and looked at a ceiling. After spending two years in one of those things all my muscles had atrophied. It was gross and excruciatingly painful. And in hospital I missed my mum and dad and big brother and lay in a state of terror and despair like a torture victim.* As an adult the much travelled Rhonda still found leaving home extremely anxiety provoking, even for domestic flights (even for car trips). *I had a dread of never returning, or of getting back and discovering that home had disappeared. I was still stuck in the feelings I had as a baby of thirteen months, when my home disappeared completely...For years after I came home from hospital, if things weren't directly in my sight, I'd think they'd gone. I even hated playing hide and seek—I might never be found.* There is much else of interest in this fascinating book. Look for it in your local library.

### **Post-polio and menopause**

Post-Polio Health International (formerly GINI) has funded research at the University of Michigan, to investigate whether women with late effects of polio experience menopause differently—physically and emotionally—than do their non-disabled peers. A group of male polio survivors was also included in the study to examine whether their well-being differed from age-matched polio women both pre- and post-menopause. The complete report is online at [www.post-polio.org](http://www.post-polio.org) (click on research). These are some of the findings: Polio women who had a natural menopause (eg not caused by hysterectomy) did so at the same age, on average, as did non-disabled women. Polio survivors were more likely to have had a hysterectomy (almost 35%) than the US average of 21%. More polio women (39%) used hormone replacement therapy than did their non-disabled peers (23%). It would be interesting to know why these differences occurred and whether they exist in Australia. Overall there were no differences in post-polio symptom severity, activities of daily living or emotional well-being between polio women who took, or did not take, HRT. Polio women using HRT did not report an improvement in post-polio symptoms. On average polio women approaching menopause were more satisfied with their lives and less unhappy than were post-polio men their age, but women who were at least five years into menopause were more stressed than their male counterparts. They also reported more severe post-polio symptoms. The authors say that the findings *suggest an acceleration of decline for women compared to men in later years; this will require further investigation*. In general, polio women in this study had an overall positive (45%) or neutral (35%) experience of menopause. Fewer had a negative experience (18%). Both female and male polio survivors reported somewhat more stress than the national US ratings for their age groups. The differences in stress levels was only substantial in the case of middle aged (45-55 years) polio women who reported much greater stress than their non-disabled peers.

#### **Elimination of vaccine related polio in USA**

The October 13<sup>th</sup> 2004 issue of JAMA (Journal of the American Medical Association) reported that the changes in US polio vaccination policy have resulted in the elimination of vaccine-associated paralytic poliomyelitis (VAPP) in the US. Prior to 1997 vaccination in the US was from the Sabin oral live vaccine (OPV). Then a policy of using IVP (Salk inactivated vaccine, IPV) for the initial vaccination followed by OVP for subsequent inoculations was introduced. In 2000 an exclusive IPV schedule was adopted. Between 1961 and 1989 an average of 9 cases of VAPP were confirmed each year in the US. Between 1990 and 1999 59 cases of VAPP occurred. No cases occurred among people who had the IPV-OVP schedule nor among those who had only IPV. The last case of VAPP in the US occurred in 1999.

In Australia IVP is recommended as the preferred form of vaccination but IVP is not as yet funded by the government, which does fund OVP. An article, titled *Polio cases slipping through the net*, appeared in the Sydney Morning Herald on October 16<sup>th</sup>. It said that *According to international guidelines, one case of VAPP can be expected from every 2.4 million doses of Sabin vaccine ...in Australia this equates to one case every three years but there have been only two probable cases since 1986*. Concern was expressed that some cases of VAPP are going unrecognised here.

#### **Polio virus escapes from laboratories twice**

*The polio eradication exercise is beginning to acquire shades of a science thriller*, according to *The Times of India*, October 6<sup>th</sup>, 2004. Polio virus has escaped twice from Indian laboratories and caused 10 cases of paralytic polio. Laboratory strains of the virus were identified in three polio cases in 2000 and in seven recent cases. A task force has been set up to investigate which laboratory(s) the viruses came from. Initially however it has to come up with a list of laboratories that store polio virus, a formidable task that may take two years as there are many private laboratories in India and there is no requirement that they be registered.

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