

### **Polio survivor solves fridge frustrations**

US polio survivor John Imre experiences the frustration many wheelchair users encounter from refrigerators. He has invented and patented the *Freedom Fridge*. According to Imre, *dodging the [fridge] door is only the first athletic feat. 'You still cannot reach up the back of the freezer or to the back of the crispers'....the Freedom Fridge sits horizontally, it's centred on a pedestal and can be raised or lowered to meet a person's height. A motor rotates the shelves until what you want is up front. Jerry Johnson, director of the Center for Innovation and Development at UW-Stout, and some graduate students took the plans and formed it into the real thing. It's clear and partitioned reminding me of rotating vending machine. ....Feasibility studies put the price at \$US1,500 to \$US2,000 for a snazzier model to around \$US900 for a more basic one, Imre said. This is the first phase of the Freedom Fridge's lifespan. They're all waiting to see if their funding request to the Christopher Reeve Foundation will be approved.* (Information and quotes from an article by Mike Moore in *Journal Times*, 4/5/06).

### **Hip protectors may not help polio survivors**

Hip protectors are specially constructed underpants with pockets on the side for soft energy absorbing padding or semi-rigid material that diverts forces to the surrounding tissue. Their aim is to prevent hip fractures of the femur if the wearer falls. Polio survivors are at high risk of falls and when they fall they are more likely than others to suffer a fracture particularly as they age. Dr Julie Silver and Dr Anne Gawne's book *Postpolio Syndrome* (2004) says that: *In polio survivors, fall pattern is often related to falling forward because of tripping or knee buckling or falling backward because of lack of balance. Thus the indication for hip protector use in polio survivors may be limited.* They note that people often cease wearing them. Reasons given are: *discomfort, too much effort, skin irritation, incontinence, too difficult to don and doff, and expenses caused by multiple pairs needed for hygiene.* An additional problem for many polio survivors, not mentioned, is that polio survivors often have hips that differ in size and a scoliosis that may make it extremely difficult and uncomfortable to wear these symmetrical close fitting pants. The book suggests that if polio survivors have a tendency to fall sideways protectors might be an option to decrease fracture risk. The *British Medical Journal* (11/03/2006) has recently published a systematic review, by Darker, Gillespie and Gillespie, of all well designed research studies (14 in all) comparing hip and pelvic fracture rates in elderly people given hip protectors compared with control groups not given protectors. The BMJ concluded, in its editorial, that: *Accumulating evidence indicates that hip protectors are an ineffective intervention for those living at home and that their effectiveness in an institutional setting is uncertain.* It asks: *Are we back where we were before hip protectors were invented? Yes, probably--although the accumulated evidence suggests that hip protectors may be effective in specific subgroups of elderly people. Such groups might include highly motivated elderly people living in the community...Until clinical trials among such groups confirm the effectiveness of hip protectors, the continued use of these devices should not be widely advocated.* So if discussing with your doctor whether hip protectors might help you, you need to consider your falling pattern and whether you can get a pair of protectors that fit

properly and comfortably so that you are prepared to wear them regularly. The lack of evidence of their effectiveness and the costs and possible discomfort involved indicate that you need to think carefully about whether hip protectors are for you.

### **A 'good read' with a polio background**

Novelist Elizabeth Berg has recently published a novel; *We are all welcome here*, loosely based on the life of Pat Raming an American who contracted polio when she was 21 and pregnant. She gave birth in an iron lung. Her husband deserted her. After three years in the iron lung she went home as a quadriplegic in a wheelchair using a portable respirator. After raising her daughter Pat returned to college and became an addictions counsellor and disability activist. The novel is set in Mississippi in 1964 at the time of the civil rights movement. The story is told from the viewpoint of Diana, Paige's (the polio survivor) 13 year old daughter. Diana is trying to break free from the authority of her mother and her Black daytime carer, Peacie, Paige battles to survive on welfare and prevent the social worker finding out how much help Diana is providing. Even inadequate carers are hard to find and Paige feels guilt about keeping her child with her. As an adult Diana says, *Despite her many obstacles, what my mother succeeded best in doing was appreciating the many forms of beauty in life—as well as its possibilities. And she relished perhaps more than any other mother could the growth of her daughter, seeing in me a part of herself set free.* Many local libraries have Berg's books.

### **Practical advice about coping with PPS**

*The post-polio experience: Psychological Insights and coping strategies for polio survivors and their families*, is a recently published book by Margaret Backman, an American clinical psychologist who specialises in helping people cope with chronic illness and disability. It covers the personal and social issues that PPS involves; in short pithy chapters with the main advice in point form. Sections include personal relationships (children, parents, spouses friends, developing new relationships), social encounters (help, the need for boundaries, changing roles), medical care (patient-doctor relationships, being part of the team), mental health (tacking stress, taking charge of your life, surviving in unsettling times) and psychological issues from the polio past such as fear of abandonment, distrust of authority, shame etc. Backman says: *The fact that someone has gone through something before is no reason to assume that it will be easier the second time around, or that the person will have a better understanding of the situation. On the contrary, having to relive the experience—an experience that the individual thought had been put to rest—reawakens anxieties and conflicts that he or she had been able to ignore for years.* The book is for sale on Amazon.com for \$US18.95.

### **Pulitzer Prize for history of polio**

David Oshinsky's book *Polio: An American story*, reviewed in Issue 67 of the Newsletter, has won the 2006 Pulitzer Prize for history for the 61 year old historian at the University of Texas. The Houston Chronicle (19/4/06) quoted Oshinsky as saying the prize is important *because it opens doors in terms of allowing you to write for a larger audience and speak in many more places.*

### **Plastic wheelchair for airports**

The French Atomic Energy Commission has developed a non-magnetic wheelchair, the PASS'PORT, made entirely of plastic polymers. It will not set off metal detectors in airports (From Mobility Magazine, 10/05).

### **Mothers of unimmunised babies**

An article, *Differences in risk factors for partial and no immunisation in the first year of life* published in the British Journal of Medicine (3/6/06) reported UK research findings on factors associated with poor immunisation status in babies. These included: having a teenage or lone parent, large family size and residence in disadvantaged areas. The researchers also found that mothers of non-immunised babies tended to be older and more highly qualified. The article concluded that the strategies used to encourage vaccination in socially disadvantaged families such as accessible or home vaccinations, are not likely to promote immunisation among older, more highly educated mothers who reject vaccination. A new approach is needed. These findings are similar to the NSW immunisation rates reported in Particles in December 2003 which were lowest in affluent Sydney suburbs such as Mosman and the eastern suburbs.

### **Polio, Autism or Neither?**

This was the headline of an article by Ronald Bailey, scientific correspondent of the American journal *Reason* (July 24<sup>th</sup>, 2006). Bailey says that the percentage of US children receiving childhood vaccination is dropping and that *vaccine resisters are more likely to be highly educated and well off financially...their chief fear is that vaccinations may trigger autism... Many parents of autistic children fervently believe that the measles-mumps-rubella (MMR) triple vaccine causes autism..... However most research suggests parents are confusing correlation with causation---the symptoms of autism just happen to emerge at about the same time as recommended vaccines are given.* Anti-vaccine activists have also argued that it was the mercury in the vaccine preservative that led to autism.

The relationship between autism and vaccination was first suggested in 1998. Since then numerous research studies have failed to find supporting evidence. In 2005, a comprehensive Cochrane (a non-profit authoritative medical group) review of 31 such studies found *no credible evidence behind claims of harm from MMR vaccination.* Furthermore in 1993 Japan dropped MMR vaccination and began vaccinating for each disease separately but autism rates have risen significantly in Japan since then. Research in Quebec, after the vaccine preservative containing mercury was removed from vaccines, found that the rate of autism rose. Some researchers believe that the rise in autism is *largely the result of physicians applying boarder diagnostic criteria for the condition in recent years.* Others disagree. *The best medical advice is that whatever the cause of autism turns out to be, parents should not let their fears prevent them from immunizing their children.* Unfortunately *many parents are wrongly discounting the dangers that infectious diseases pose for their children because many have never seen a child afflicted with polio or whooping cough.* To read the full article go to [www.Reason.com/rb/rb0706.shtml](http://www.Reason.com/rb/rb0706.shtml)

### **Adults at risk of polio**

Increasing numbers of people world-wide are vulnerable to polio because they have never been exposed to the disease according to health experts quoted on the BBC news (27/7/06). *Adults who missed being vaccinated as children and who have not*

*been exposed to the wild virus are most at risk.* In the current epidemic of polio in Namibia, which had been free of polio since 1995, most of those who contracted the disease have been between the ages of 15-45. *In contrast, most polio outbreaks affect children under five. The disease is more likely to cause paralysis in adults. Last month a campaign was launched to immunise the whole population of Namibia against polio. People can develop immunity to the disease by being infected naturally, through vaccination or by catching the live, but weakened, version of the virus which is in the oral vaccine from newly immunised children.* However with the switch from the oral to the safer Salk vaccine in industrialised countries this indirect source of protection for unvaccinated people has ceased.

### **Knitting and sand sculpture encourage polio vaccination**

Cilla Webster, editor of *The African Connection* (newsletter of the Post-Polio Network RSA, January 2006) has initiated the KNOT/CROCHET FOR POLIO campaign to encourage unemployed and poor families to bring their children to polio vaccination clinics. According to Cilla: *Although the vaccination is free, the transport to the clinics isn't. A knitted garment or blanket encourages those who live in poverty to give up a meal to bring their children to the clinic because they know when the child has been vaccinated they will receive something warm to wear, something they would otherwise not be able to afford. In December 2005 I received a thank you letter to say polio immunisation had gone up 5% in our area which means this campaign is really working.* Cilla's email address is [cillawebster@polka.co.za](mailto:cillawebster@polka.co.za)

Indian artist Sudarsan Patnaik built a large sand sculpture of a mother and child to spread the message of polio eradication. The sculpture which took 36 hours to build was erected on tsunami damaged Pondicherry beach. Watched by thousands the Tourism Secretary unveiled the sculpture using two polio drops.

### **'Warm Springs' available on DVD**

In the December 2005 I wrote about this film, which covers the early years of President Roosevelt's life with polio. It was then showing in the US and is now available on DVD in Australia. Having seen it I recommend it highly.

### **Guerrilla disabled parking campaigns**

Coolz0r a website blog where people can post their thoughts about marketing and advertising, recently reported an *interesting guerrilla campaign that targets reluctant, good-functioning and abled drivers who keep parking on the wrong place, making it difficult for disabled people to use what's rightfully theirs. The strong language is actually strengthening the message.* Three of the signs which feature the disabled wheelchair symbol can be seen on <http://blog.coolz0r.com/2006/07/10/your-spine-or-mine>. One caption reads; *'This parking space is for disabled only. Everyone else: THANK GOD yours is still over there, a bit further'*. Another advises: *'If it's hard to grasp why disabled people need this space, WE SUGGEST: Go and break your f---ing spine'*. One warns: *'MANY OF THOSE [who] used to park here illegally now do so legally. Is fate trying to tell you something?'* One of the comments posted on the site says that police in several US states have run checks on people parking in disabled spaces illegally. *They found many had criminal charges and arrest warrants following them like tin cans tied behind a 'Just Married' jalopy....Why such a high percentage? A psychologist speculated that law breakers are law breakers in small things as well as*

*big. The police also found that many of the nasty parkers had only just committed a crime and were in 'I'm bullet proof' mode! Why aren't we brave enough to walk up to these people and ask them about their disability? Because they're probably carrying a gun...Instead, push a potato up the exhaust pipe...and run!* From the blog on the Disability Studies website at Temple University, Philadelphia, I learnt that the signs are translations from a 2004 award winning Latvian campaign by the Riga agency ZOOM. This blog also describes a campaign by the organisation for Equal Rights in Brussels. They place a ticket under the windshields of illegally parked cars which reads: *'YES: I would like to park here again, SO I CHOOSE: amputation left leg, amputation right leg, paraplegia, multiple sclerosis, spina bifida'*. There are boxes to tick.

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