



POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

Welcome to the last *Network News* for 2003 which has plenty of interest to keep you informed over the Christmas holidays.

At the Network's fifteenth Annual General Meeting held on 29 November the following members were elected to the Management Committee:

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|-------------------|-----------------------|-----------------|
| Gillian Thomas | <i>President</i> | Bing Kwong Mak |
| Merle Thompson | <i>Vice-President</i> | Alice Smart |
| Ann-Mason Furmage | <i>Secretary</i> | Neil von Schill |
| Bob Tonazzi | <i>Treasurer</i> | John Ward |
| Anne Buchanan | | Mary Westbrook |
| George Laszuk | | Bryan Wishart |

Long-time supporter Janet Malone did not re-stand for the Committee this year and we thank her for the commitment she has given over the last four years, and in her previous term of office. Janet has capably served members over many years in the roles of Vice-President, Treasurer and, most recently, Secretary. She now leaves to pursue other interests and although sorry to see her go, we wish her well in her future community work.

Following the lunch break after the AGM, we heard a very interesting and informative presentation on *Obstructive Sleep Apnoea* by Dr David Barnes, Clinical Associate Professor in Medicine at the University of Sydney and respiratory physician at Royal Prince Alfred Hospital, where he is also a member of the Sleep Disorders Unit. Roving reporter Wendy Chaff is generously writing up Dr Barnes' talk for the benefit of members unable to attend, and her report will appear in the next issue of *Network News*.

The Management Committee will be holding its annual planning meeting in January where we will discuss and decide on our goals for the upcoming year. If anyone would like to make suggestions for Network services or activities over the coming year for consideration by the Committee, please get in touch with me **before 19 January 2004**.

If your address label still reads "Renewal Due on 1 July 2003" we have not yet received your membership renewal. In this case, you will find another copy of your Membership Renewal Form enclosed. Please send in your membership subscription as soon as possible. The Network is self-funded and needs your continued support to enable us to keep providing services to polio survivors and their families. If you decide not to renew, please tell us why. We need to know if we are not meeting your needs.

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Stem Cell Therapy for Post-Polio Syndrome

Edward P Bollenbach, BA, MA, Professor Emeritus in Biology

Northwestern Connecticut Community College, Winstead, Connecticut

Edward P Bollenbach (edwardbollenbach@snet.net) received a BA in Biology and an MA in Biology from the State University of New York at New Paltz, New York. In his professional work, he focused on bacteria and fungi and, as he began to experience polio's late effects, he decided to use his scientific knowledge to clarify information about post-polio syndrome.

He co-authored an article in 2002 with Marcia Falconer, PhD, Ottawa, Ontario, Canada, "Late functional loss in nonparalytic polios", AM J Phys Med Rehabil, Jan-Feb, 79(1), 19-23.

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The media is abuzz with talk of stem cells, and there is hope of curing diseases, such as Parkinson's and muscular dystrophy, and spinal cord injury, using stem cell technology. What about polio? It was delightful to see a press release from the Salk Institute this spring, which added post-polio syndrome to the list of targets for stem cell therapy.^[1]

A refresher on stem cells

There are two broad types of stem cells with several subtypes:

Embryonic stem cells are derived from the human blastocyst — the result of five days of cell division after sperm and egg fuse into a fertilized egg (zygote). The human blastocyst is a sphere with about 30 stem cells inside, and these cells have many useful properties for therapy. Prodded with chemical messengers, they can develop into most of the cells of the adult body; that is, they are pluripotent. In a lab dish, they can be maintained, dividing into new stem cells, for more than a year. They could easily be used for production of nerve cells or muscle fibers for post-polio therapy.

However, since the stem cells are not from the patient who will use them, they are easily rejected. This problem can be solved if the stem cells are cloned first by the patient donating a nucleus to a human egg cell and then allowing five days for development until stem cells are evident in the blastocyst. This is called *therapeutic cloning* or nuclear exchange. Therapeutic cloning requires new legislation and is currently not supported in the United States. Further, embryonic stem cells can transform into cancerous cells easier than the second type of stem cell, or adult stem cells.

Adult stem cells exist in many parts of the body, such as in the bone marrow, brain, blood, muscle, and internal organs. They are difficult to isolate because, in comparison to the tissue they are within, they represent a very small fraction of cells. However, many adult stem cells are pluripotent and can be prodded to develop into muscle, nerve, skin, and a variety of cell types. Because the patients can provide the stem cells for their own therapy, the stem cells are not rejected. Adult stem cells are not as prodigious as embryonic cells and cannot be maintained in the lab as long. Theoretically, as the technology progresses, adult stem cells should be able to serve as cellular material for new nerve cells and skeletal muscle fiber.

Some procedures may require embryonic stem cells and others may do better with adult stem cells.^[2] In the United States, there are currently very few samples of embryonic stem cells available, which government grants can fund. The American Medical Association recently lobbied to have this reconsidered. No news yet.

Challenge for use in old polio

Old polio presents several challenges that are different from the disorders usually discussed as targets for stem cell therapy. For example, in a spinal cord injury there is a loss of cells at the break in the spinal cord — where the body of nerve cells resides. Outside the cord, each cell projects into a long tube, sometimes three feet or more, which ends at a muscle fiber within a muscle. Theoretically, these long tubes, or axons, end with a few branches that connect to the muscle cells. In a spinal cord injury, these fibers and axons within the peripheral muscles usually remain intact. What needs to be done is to connect a new nerve body with the axon already there.

In post-polio syndrome, it is the end branches of the axons that are dying off while the nerve cell itself may continue living or eventually die. If scientists successfully implant new nerve cells in the anterior horn of the spinal cord, can the cells extend axons and connective end branches out through the tissues to a target muscle fiber? In polio, once muscle fibers have lost their nerve connections, they struggle to survive. Muscle fibers typically will atrophy and become non-functional after losing nerve stimulation. Therefore, muscle fibers may also need to be replaced. This is much more difficult than implanting new nerve cells in one place such as in Parkinson's disease or spinal cord injury.

Yet, there are things that can be done. For example, new nerve cells or support cells can be implanted to either fuse into existing weak motor nerve cells or provide protective chemicals for support.^[3] This would allow existing motor nerves to function longer and possibly even sprout more.

Another approach may be to try to strengthen muscles closer to the spinal cord. Muscles such as the paraspinal or hip muscles, if damaged, can result in more disability than more distant muscles, like the calf. So it may be possible to have a positive impact on muscles at or above the hip, where they cause the most disability if weakened. Regardless, there are several promising approaches, including the use of scaffolding biological materials, such as chondroitin, to guide new nerves to their targets.^[4]

Several signaling factors act between stem cells, allowing them to differentiate and grow in the lab or in the body. As stem cell research progresses, more of these growth and differentiation factors for cell specialization, adaptation, and connection should be uncovered.

Looking ahead

Imagine a combination of mechanisms (some of which are already known) that can signal motor neurons (nerve cells) to form connections with new muscle fibers. Muscle signaling cell adhesion molecules can attract the placement of nerve synapses (connections) to muscle. Without even using stem cells, new derivative cellular chemicals can guide cells to the proper muscle fibers in a trouble area. There are many other possibilities. The only question is how long will it be until effective therapies emerge from stem cell research.

Much of the advancement in stem cell therapies and much of the realization of future promise will come as a result of lab work using model organisms like mice. A model of spinal cord damage, resulting in complete paralysis, has been mitigated in a rat with neurons derived from mouse embryonic stem cells. After treatment, the rat was able to use its hind legs in walking motions where as prior to treatment it could not.^[5]

Rodents can be easily engineered genetically and cloned, without implanted cell rejection. Using a mouse as a polio model (*Polio Network News*, Vol 18, No 4, and *Network News*, Issue 57), there is a new opportunity to study post-polio rehabilitation with stem cells. The possibility of using this polio mouse model for stem cell studies involving polio is clear, due to the success in using rodents to further the understanding of cell differentiation and the possibilities of stem cell therapy.^[6]

The most vexing problem for polio survivors may be the speed at which stem cell therapy advancement occurs. The clock is ticking. If rapid advancement in the use of this technology occurs in the next ten years or so, those who had polio in the '40s and '50s may benefit. If not, these polio survivors may just miss the next milestone in medicine — the ability to regenerate muscle and nerve tissue.

So close to the remedy, and yet so far.

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- [3] Murashov, Alexander K, Assistant Professor in Physiology East Carolina School of Medicine. Personal Communication.
- [4] Murashov, Alexander K (2003). *Development of a method for generation of spinal cord neurons from embryonic stem cells for treatment of spinal cord injury.* Retrieved from <www.ecu.edu/physio/labakm/Stem%20Cells.htm>.
- [5] Stem cells help spinal cord damage. *News from Science.* Retrieved from <www.abc.net.au/science/news/stories/s69828.htm> (Nov 30, 1999).
- [6] Mouse model developed for post-polio research (2002). *Polio Network News*, 18(4). Reported in *Network News*, Issue 57.

New Book Updates Post-Polio Research and Treatments

Mary Westbrook

This is a review of *Postpolio Syndrome* edited by Julie Silver, MD, Medical Director of the International Rehabilitation Center for Polio, Framingham, Massachusetts and the late Anne Gawne, MD, Director of the Post-Polio Clinic at Warm Springs. The 323 page book of 18 chapters, which has just been published by Hanley & Belfus, Philadelphia, is aimed at health professionals but will be of considerable interest to polio survivors who want in-depth coverage of a postpolio topic for themselves or their health practitioners. In 2001 Yale University Press published Silver's book, *Post-Polio Syndrome: A guide for Polio Survivors and their families* (which is often on bookstore lists as *Post-Polio Syndrome*). It was reviewed in *Network News* Issue 51, November 2001. I have emphasized details of the two books as the similarity of their titles could easily result in you ordering the wrong one.

The initial chapter by Dr Lauro Halstead discusses the diagnosis of PPS. He has written about this many times but now, while he still lists the commonest problems as fatigue, weakness and pain, there is greater emphasis on new weakness which he describes as *the cardinal symptom of PPS*. From his clinical experience he proposes four subtypes of polio survivors diagnosed with PPS. *Type I, or 'indeterminate' diagnosis, represents approximately 5-10% of individuals seen in a clinical setting. Generally, their involvement was not severe at onset and their symptoms are relatively mild. They may make a few modifications in their lifestyle and upgrade their bracing, start using a cane, or start an exercise program. These interventions are typically followed by the individuals regaining their lost strength and then remaining stable.* He says that the majority of this group probably has disuse weakness rather than PPS. Because of this reaction in some patients Halstead suggests that survivors be reassessed 3-6 months after the initial consultations before confirming a diagnosis of PPS. People with Type II (about 50-60%) are described as having 'stair-step' PPS. *After intervention, they may stabilize for a period of several months or even several years. This is followed by additional loss of strength and function that prompts the individual to make more interventions.* This cycle repeats itself. Most of these people have PPS. Type III comprises 3-5% of people with PPS. *They usually had fairly severe polio at onset and then made a good neurological recovery. They have often led very active lives. Despite conscientious efforts to implement interventions, they tend to pursue a mostly benign but relentless downhill course. If there is an immunologic component to PPS, it would most likely be present in this group.* All of these people have PPS. Type IV (25-35%) experiences some combination of the clinical histories of the other three types.

Dr Daria Trojan and others discuss *Evaluating and treating symptomatic postpolio patients*. This topic is developed in further papers focusing on joint and muscle pain, postpolio fatigue, speech and swallowing difficulties, electrophysiology and pulmonary dysfunction. A chapter by Gawne describes the interdisciplinary team at Warm Springs viz rehabilitation nurse, physician, physiotherapist, occupational therapist, orthotist, respiratory therapist, pharmacologist, dietitian, and speech pathologist. They provide their services over a 2 or 3 day period. Sadly it has probably taken you years to assemble your team of no, one or two helpful practitioners!

A pleasing feature of the book is a chapter on *Screening and treatment of the polio foot and ankle*, by Brent Bernstein, a podiatrist, and Anne Gawne. This topic is rarely mentioned in the polio literature. I discovered that the reason why the tibialis anterior and quadriceps muscles are particularly vulnerable to paralysis in polio is because they are innervated by short columns of anterior horn cells and hence easier for the virus to put out of action. The intrinsic muscles of the foot and the long extensor muscles are less vulnerable. The

authors distributed 150 questionnaires via a polio support group newsletter. Of the 83 survivors who completed it, 89% said they had a foot deformity, such as length discrepancies, hammer toes, drop foot or osteoarthritis, 54% reported foot pain and 73% a cold extremity. Only 8% were receiving podiatric care despite evidence that such treatment can be very effective. Various, primarily non-surgical, solutions to foot problems are described. The chapter concludes with the following advice regarding surgery: *Any surgeon attempting reconstruction of the lower extremity in a polio patient must have expertise in the anatomy and bio-mechanics of the polio foot. Last but not least, the surgeon should have basic knowledge of PPS itself so as not to fall into the trap of chastising patients to 'work harder' only leading to frustration, increased weakness, and pain for the patient. As Frederico Stelo-Ortiz stated, 'The eradication of poliomyelitis in highly developed countries resulted in neglect of facilities once available for acute, subacute and residual cases. Physiotherapy and rehabilitation departments and diagnostic and therapeutic facilities disappeared or were converted for other uses, as no more cases were seen — when a sporadic case of poliomyelitis presents, residual paralysis is incorrectly managed, jeopardizing the life of the patient by improper surgery or fitting of the wrong brace'. And so say all of us!*

A chapter on *Aging with polio* by physiotherapist Dorothy Aiello and Julie Silver concludes: *For people with a history of polio, aging is more challenging as we have an increased risk of co-morbidities (for example, respiratory disease, osteoporosis, fractures) and the changes that occur in muscles with ageing result in further limitations of polios' functioning. They suggest that if a patient has a tendency to fall sideways, a hip protector may be a possible option to try to decrease fracture risk ... In polio survivors, fall pattern is often related to falling forward because of knee buckling or falling backward because of loss of balance. Thus, the indication for hip-protector use in polio survivors may be limited.*

James Agre, MD, reviews research into the role of *Exercise in the treatment of postpolio syndrome*. His own research has shown that polio survivors' muscles have less endurance, that is, take longer to recover. Thus survivors can *perform much greater work with less muscle fatigue and greater strength recovery when they stop to rest at intervals*. He concludes that: *The peer reviewed literature does demonstrate that exercise can be beneficial in selected individuals with PPS. The caveat is that not all individuals benefit from it. Some have increasing difficulties and problems because the exercise exceeds the individual's tolerance for activity. The exercise in postpolio individuals should be carefully monitored. ... when a postpolio individual exercises, he or she should avoid activity that leads to excessive fatigue, muscle pain, or joint pain. Exercise beyond that level of activity may simply lead to overuse problems.* In a chapter on *Physical therapy in the management of chronic poliomyelitis and postpolio syndrome*, Elizabeth Dean and Marijke Dallimore also cover exercise issues. I was disappointed that these chapters had little to say about the effects of stretching exercises due to lack of research. I have found gentle stretching very helpful in reducing pain and increasing range of movement. However Dean warns that some polio muscles should not be stretched as they provide stability, particularly when a joint has been surgically fused.

Kathryn Smith, aquatic program director at Warm Springs has a chapter on *Aquatic therapy for polio survivors* particularly directed at practitioners running such courses. She recommends evaluation of polios before they begin a program. *The cardiac, renal and respiratory systems are taxed to a greater degree when a person is submerged in water. ... Patients with weakness or paralysis in the muscles of respiration, as is common with polio patients, may have increased awareness of the hydrostatic pressure of the water's pushing in on the thoracic area. This may or may not be associated with increased difficulty of breathing, even when oxygen saturation levels remain stable. ... For most patients, this is a sensation they grow accustomed to. ... Still therapists may choose to decrease the*

amount of submergence of the patient's thorax by adjusting the depth at which aquatic therapy is performed. She recommends: For polio survivors, particularly those with PPS, water temperature between 90 and 92 degrees F. ... and these patients should begin an aquatic exercise program with a short session, often just 10 minutes of time in the water. The length of time should be gradually increased as the patient demonstrates increased endurance without increased fatigue.

The role of occupational therapy in the management of polio survivors is covered by Beth Kowall. Occupational therapists Maria Cole and Laura Ryan discuss Energy conservation and pacing. Claire Kalpakjian and others write about Psychological well-being of polio survivors. They refer to Australian research findings showing, on average, a decrease in survivors' emotional distress over a five year period as they learn to cope with PPS. There have been similar results in Norwegian research. Australian findings that polio survivors find it difficult to seek help and emotional support from others are similar to Swedish findings that polio survivors were less likely to seek social support than a nondisabled control group. The Norwegian researchers found that survivors who reported being psychologically harmed by their early polio experiences were those who found it particularly difficult to talk to their families about polio and who felt less supported by their families. Various studies have found factors associated with emotional distress in polio survivors. Physical factors include greater pain and fatigue, less mobility, not having visible signs of disability before the onset of PPS. Psychosocial factors include feeling unable to control one's health, low satisfaction with social relationships, traumatic early experiences with polio, living alone, lack of understanding doctors. Some studies have found higher rates of clinical depression among polio survivors but others have not.

Other chapters include Powered mobility for polio survivors and Gait, orthoses, footwear and assistive devices. The authors discuss the energy expenditure and risk damage associated with various aids. Compared with unilateral device use, bilateral assistive devices provide more stability and decreased joint stress. Research has shown that using a standard walker requires 212% more oxygen per metre than unassisted walking and 104% more oxygen than with a wheeled walker. Pivoting wheels of increased size (approximately 5 inches in diameter) are more easily maneuverable than the standard 3-inch nonpivoting wheels.

Postpolio Syndrome is available on-line from Amazon.com for \$US37 and from DA Books, Melbourne (03 9210 7788) for \$67.86 plus postage.

Polio Story in TV Drama Series

In the USA NBC is showing an award winning series, American Dreams, which is set in the 1960s and is described as being a unique time capsule. The main characters, the Pryor family in Philadelphia, include son Will who wears a leg brace as a result of polio. Dr Richard Bruno has worked with NBC to ensure that Will is accurately depicted. In an interview with New Mobility magazine Bruno said 'Having a polio survivor as a character was a unique opportunity to tell the story of what having polio as a child was really like'. The storyline is realistic as many childhood polio survivors underwent complicated surgeries and painful physiotherapy ... parents wanted to get rid of any evidence of polio – like the Pryors wanting to remove Will's brace – and to make children appear 'normal'.

This TV series is now on in Australia. It screens in Sydney (and all other mainland capitals) on Channel 7 on Friday evenings from 8:40 – 10:40 pm, re-titled Our Generation. We expect that Will's surgery episodes won't screen until the New Year.

Bruno advises that during the screening in the USA, NBC aired a public service announcement about Post-Polio Sequelae (PPS). We will be approaching Channel 7 to similarly screen an announcement about PPS and the Network at appropriate points in the storyline.

And Then There Were Four And More

Bryan Wishart, October 2003

Regular readers will remember reading member Bryan Wishart's story of "Three Young Men" in Network News, Issue 54, June 2002. Bryan has been a committed and generous supporter of the Network since he first made contact with us in 1999. Although not a polio survivor himself, he has gone out of his way to help and encourage young polio survivors. As the title of this article suggests, Bryan is not resting on his laurels.

Until three years ago, I had not been to Mumbai (newer name for Bombay), in India, since 1974. Yet it had not seemed to have changed that much over that time horizon. Still wall to wall poverty. And that, in itself, is a contradiction. Mumbai has a lot of wealth. It is the financial centre of India and the film capital (Bollywood).

Driving through the streets, you can see people living by the side of the main thoroughfares, at best with a tarpaulin covering their makeshift home. Other poor families, who are better situated, live in slum areas.

Sitting in a car or taxi at traffic lights, there are always beggars; the poor and the disabled. This is a nation of more than 1 billion people. The Indian government does not seem to have an answer for the disadvantaged. Many agencies try to help. What can an individual do? Certainly not solve world hunger. When confronted by a family (grandmother, mother, son, baby in arms) asking for 1 rupee (3 Australian cents) and for a banana for baba, what do you do? You help one, you help the next, and on it goes. I struggle with that.

Six years ago I decided to help a young man with polio. This progressed to two and then three, working with them to improve the quality of their lives and to give them a chance to make the most of their potential: health, education, sport, work, life in general. This started with a Korean (Lee, Chi Won) and then two Taiwanese (firstly Liu, Zhang-zhong and then Tsai, Tsung-Ta).

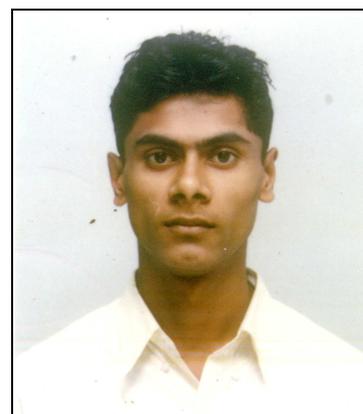
In April 2002, I was having brunch with friends of mine in Singapore; an Indian family. The husband and wife knew about the three young men, to whom I provided some sort of support. Out of the blue, the wife said to me "Why don't you support an Indian young man with polio?". After very little consideration, my response was "OK. Find him for me."

It was not easy. But after much effort, getting input from her doctor parents in India and surfing the internet, she put me in touch with an organisation in Mumbai.

I contacted that organisation with details of the type of person I was looking to support and why. They took about a week to review candidates and then they put forward a 20 year old, Vilas Mehabubani. We started communicating by email and then by telephone in June 2002.

Vilas is from a poor family. He has a mother (Saroj), older sister (Kavita) and younger brother (Vikas). His father died when Vilas was two years old. He and his family are Christians in a country dominated by Hindus and Muslims.

Vilas contracted polio when he was only a few months old. Fortunately, if that is the right word, it only affected his right leg. I do not know if it is a particular strain of polio but, in Mumbai, many people who have contracted polio have been affected in only one leg.



Vilas told me he lived in a slum area in a home that is 10 foot by 10 foot. I could not comprehend this. I realised that his sister lived with her grandparents because the home was so small. But how could even three adults live in such a small "room". I was to find out later. The good news is that he and his family, including his sister, have moved into an apartment that is at least five times the size of their current home. What luxury!

Three months after we started communicating, we met face-to-face in Mumbai. Vilas came to my hotel and I met him from his taxi. Huge smile on his face and on mine.

We had a great first day together: talking, eating, shopping. Together, we developed a plan for Vilas, mainly around education and fitness.

This was a dream come true for Vilas. Years before, standing outside a five star hotel in Mumbai, he said to his family that one day a foreigner would take him to a hotel like that.

Vilas wore a full-length leg brace that he had been given by a hospital. It did not fit properly. His ankle was bound in cloth to protect it from chafing. The knee lock was stiff, making it difficult to lock and unlock. We agreed, there and then, that Vilas needed to get a new leg brace that was made for him and fitted properly.

The following day, we went to visit the organisation that had introduced Vilas to me. It is working very hard to help the disabled in the nearby slums. I had a lengthy chat with one of the founders and the person who had put Vilas forward to me, mainly discussing Vilas's future. It was good to spend time with them.

Then, off to meet Vilas' family. When we got out of the taxi, I could see row upon row of slum dwellings. But the impression that sticks with me is all the young children running around, smiling and seemingly content and happy.

Vilas' mother, sister and brother were standing outside the shop front by the entrance to their home. His family was so happy to see me. I entered this 10 foot by 10 foot dwelling; ironing table on the right, living/sleeping floor in front, kitchen to the left and bathroom in the far left-hand corner. The communal toilet was some way from their home.

A chair was unfolded for me and then they fed me delicious Indian food cooked by Kavita. We talked a lot and got to know each other very well. Wonderful experience.

Since then, I have visited Mumbai a number of times. Each time, Vilas has come to stay with me in my hotel for the duration of my visit; eating, swimming, gym. What a difference for him. The hotel rooms were all bigger than his entire home.

On these visits, I also usually met Vilas's family and had lunch or dinner with them at least once. The first time they came to the hotel, in which I was staying, was the first time they had been inside a five star hotel. What an experience for them. And what joy for Vilas to be able to share such an experience with his family. His family was so grateful to me, wrote me letters of love and appreciation and gave me small gifts. It also became a habit for Vilas to bring me a basket of flowers when he came to stay with me at the hotel.

I encouraged Vilas to exercise his polio leg and to do more swimming and gym work. Also, with the new full length leg brace, I got him to build up his shoe by one inch. Outstanding result. He was able to walk much better and he felt more confident.

This was the same young man who, as a teenager, would wrap his polio leg in cloth to make it appear, through his trousers, to be the same size as his other leg. So, no longer a feeling of being ashamed.

What next? I encouraged him to wear shorts. Then swimming became an addiction to such an extent that he wants to represent India in the Athens Paralympics as a swimmer. He also took up English study. And, with all the exercise and swimming, he changed to a below-the-knee leg brace.

Vilas has a warm, caring and loving personality. This is coupled with a positive, can-do attitude. These traits have given him the strength of character necessary to provide support for his mother, sister and brother as the senior male member of the household.

These characteristics also led him to a decision to help other less advantaged people.

Someone Vilas had met when he was doing some computer study also has polio (left leg). So, Vijay became the first person that Vilas helped. Vilas encouraged Vijay to go swimming with him and paid the fees. They also went to movies together. They have built up a very good friendship.

Vijay's full length leg brace was another example of a badly fitting device. Just like Vilas', it had to be replaced. Vijay now has a new leg brace and walks with greater comfort and confidence. What a difference feeling good about yourself makes.

Other examples of Vilas' kind heart include paying fees for a course for a young woman with polio and giving some money to the League of Mercy, a home for young girls with no parents.

Part of Vilas' plan is for him to come to Australia to improve his English further and to study computers at University. The best laid plans! The X-Rays he had, as part of the medical associated with getting a visa, showed a large shadow on his lung: tuberculosis.

The hat-trick. First polio. Then, as a very young boy, being covered in acid from a jar thrown by hoodlums. This almost killed him. The result is scarring of his right arm and right leg. And, now, tuberculosis.

To date, his visa for Australia has not been granted. He has been taking medicine to address the tuberculosis, for some time, with very good results.

We have not given up. We will persevere to get the visa so that Vilas can achieve another of his goals, which is to visit Sydney, his dream city.

This is not about someone with a disability nor someone from a poor family background. It is about someone with courage, belief, determination and commitment.

Sometimes, dreams do come true.

Postscript On 9 December Bryan flew to India to bring Vilas back to Australia for a three month stay. He reports that this will be Vilas' first plane trip and he is very excited.

Wrap-up of Post-Polio Awareness Week 1 – 7 November

This year we issued two different Media Releases, the first focussed on informing polio survivors and their families about the late effects of polio, while the second included a message about the importance of immunisation.

Gillian did radio interviews with SBS Radio (in conjunction with Network member Carmelita Bongco), Australian Radio Network, 2LF in Young, 2SM in Sydney, with Mark Vale in his *Morning Show* on ABC Radio in Bega, and with Janice McGilchrist in her *Morning Wireless Program* on Radio 2BS in Bathurst. Thanks to members' efforts, items appeared in the *Illawarra Mercury*, the *Newcastle Herald*, the *Shoalhaven & Nowra News* and the Port Macquarie press. Our most far-reaching publicity came from an article in *The Australian Senior*. Finally, trying something completely different, we had an Awareness Week message displayed on a large sign outside the Blue Mountains District Hospital.

We were kept busy sending out information kits after all the publicity. A big thank you to those members across the state who put up posters and mounted displays, distributed pamphlets, and participated in media interviews to support our Awareness Week activities.

Polio Particles

Mary Westbrook

Polio Particles is compiled by Mary Westbrook as items in the press or professional journals catch her eye. Included in this series are brief reviews of books on polio or post-polio, updates on post-polio research, information about immunisation and the status of global polio eradication, and other items of interest.



Court orders polio vaccination

In England the high court ruled, in two separate cases, that two girls be given vaccines appropriate to their age, against their mothers' wishes, after their fathers fought to have them immunised (*Guardian* 13/6/03). Both sets of parents are separated and the girls live with their mothers. The mothers argued that *immunisation involved unacceptable risks and that even if the court decided it was in the girls' best interests, it should not use its powers to make an order*. One mother had never been immunised herself and said she had not come to any harm and did not believe her daughter would. The other mother said that immunisation was a *total rejection* of her holistic approach to life. The judge ruled that the benefits of vaccination outweighed the risks and ordered that the girls be immunised against polio, diphtheria, tetanus, whooping cough, meningitis, rubella, measles, mumps and tuberculosis. The judge said that: *Where parents are in agreement that their child shall not be vaccinated, the law and doctors respect that view ... The issue only arises before me because two sets of parents ... are not in agreement*. On 30/7/03 the *Guardian* reported that when the mothers appealed against the decision the three appeal court judges upheld the high court ruling saying that the girls' best interests were served by being vaccinated. One judge described the medical evidence relied on by the mothers to support their case that vaccination was dangerous and unnecessary as *junk science*. One of the mothers is considering taking the case to the House of Lords.

Conscientious objectors to immunisation in NSW

A unique feature of the Australian Childhood Immunisation Register (ACIR) is that it provides conscientious objection (CO) forms that parents can complete. The NSW Public Health Bulletin (Jan-Feb 2003) published a study by Brynley Hall and Peter McIntyre of immunization coverage and conscientious objectors in the state. They point out that all objectors do not register. This is particularly the case in economically advantaged areas where parents have less incentive to fill in the CO form so that they are eligible for means tested child-care benefits. The authors found that *immunisation coverage for children 'fully immunised at 12 months of age' for NSW was around 90%*. Outside Sydney, coverage was lowest in the north coast areas of Lismore and Richmond-Tweed (including Byron Bay) and in the lower south coast which includes the Bega Valley. In Sydney coverage was lowest in the inner urban areas (as low as 77% in Mosman and less than 85% in Waverley, Woollahra, South Sydney, Ashfield and Strathfield). The proportion of the state's children fully immunised at 2 years of age is around 88% which is quite similar to the one year figure. The proportion of conscientious objectors was only 0.4% of the number of children who were eligible for vaccination. However CO levels were particularly high in four areas: Lismore (4.2% of eligible children), Richmond-Tweed (3.1%), Port Macquarie, the upper Murray and Snowy Mountains, and the Blue Mountains. In Byron Bay 9% of children in the 1-2 age range are registered as COs. The authors conclude that immunisation rates in some areas of NSW are sufficiently low for outbreaks of disease to occur among groups of COs. This recently occurred on the Whitsunday islands where there was an outbreak of measles.

Destruction of stocks of polio virus

The *New York Times* (29/7/03) reported that WHO is attempting to discover what stocks of polio virus exist around the world and is encouraging laboratories to tighten controls to prevent accidental release of the virus. So far 80 countries have provided inventories. *Two countries — Oman and Vietnam — have destroyed all known stocks of the virus there. Many laboratories in eight other countries have destroyed their stocks, even though WHO has not required them to take this step. The eight countries are Albania, Bahrain, Cambodia, Hong Kong, Mongolia, Morocco, New Zealand and Singapore ... Because polio virus is needed to manufacture the vaccine, a number of countries will need to maintain stocks of the virus. WHO is encouraging laboratories to destroy stocks of polio virus unless they are conducting top priority scientific projects or have a clear scientific reason for keeping the virus. Also, to prevent accidental infection or escape of the virus that could start new outbreaks, particularly in polio free countries, WHO is encouraging scientists to work with polio only in laboratories that are rated as P-3, the second strictest of the four levels of bio-security. Dr Bruce Aylward at WHO, said that obtaining reliable inventories 'is proving to be a big logistical challenge but very definitely a manageable one'.*

Recent polio statistics

In 2001 there were 483 cases of polio worldwide according to MMWR (Morbidity Mortality Weekly Reports) 25/4/2003. In 2002, polio cases increased to 1,920. This substantial rise was largely due to an epidemic in India. It began in Uttar Pradesh and spread to other states. This year there has been a new outbreak of polio in northern Nigeria that has spread to areas that had not had a case for since 2001 (Associated Press 23/10/03). A dozen children in neighbouring countries of Ghana, Niger, Togo, Burkino Faso and Chad have been paralysed. DNA from these patients' viruses traces all cases back to Kano in Nigeria. Overall Nigeria has had 178 of the 414 cases of polio that had occurred in the world that year up to October 14. The outbreak began in Kano last summer. Experts blame insufficient immunisation coverage with only 16% of children vaccinated. For every child paralysed it is estimated between 200 -1,000 catch the virus. Bruce Aylward, who coordinates the Polio Eradication Initiative at WHO, is quoted as saying: *Nigeria has gone backward ... and is the last major challenge on the road to global polio eradication.* WHO plans more polio immunisation days in December and January and greater surveillance of the disease. Of this year's cases, one was in Lebanon. This case (from India) was Lebanon's first case in ten years.

If the polio eradication program fails

The *Guardian* (15/5/03) discussed the problems of implementing the last stages of the WHO program to eliminate polio. Bruce Aylward, the program director, is quoted as saying: *In 2005 we may be looking at one of two things — the extraordinary accomplishment of the eradication of a disease, or looking back and saying we botched it — we were down to 2,000 cases and we didn't come up with the money to finish the job. That's what people don't understand — in ten years if we don't finish it, there won't be a thousand cases of polio. There will be a quarter of a million.*

PD James mentions the late effects of polio

I have given examples in several *Polio Particles* of references to the late effects of polio occurring in popular literature. No doubt this reflects greater community knowledge of the problem but also spreads awareness. I am currently reading and enjoying PD James' latest murder mystery, *The Murder Room*. In the book a character comments, *One would wish in old age to remember only the happiness of life. It doesn't work that way, except for the lucky ones. Just as polio can return in some form and strike again, so can the past mistakes, the failures, the sins.*

FDR's polio questioned

During October there were many media reports about an article in the *Journal of Medical Biology* by paediatric immunologist, Dr Armond Goldman and colleagues at the University of Texas. In it they argue that President Roosevelt (FDR) had Guillain-Barré syndrome rather than polio. Guillain-Barré syndrome occurs after people have had a virus or infection and the body's immune system turns on brain neurones causing paralysis. They base their case on several facts. Firstly, FDR's age was 39 when he became ill and most polio cases were young children. Secondly, his pattern of paralysis (on both sides of the body) is more common in Guillain-Barré than polio. Also the immunologists argue that FDR's fever was accompanied by the onset of paralysis whereas in many polio cases the fever precedes the paralysis by several days. Goldman says that the fact that the weakness in the arms and face disappeared while the legs remained paralysed, the extreme pain and the bowel and bladder dysfunction, and the duration of the progression of FDR's paralysis all point to Guillain-Barré. However many neurologists and post-polio specialists disagree. *Newsday* (31/10/03) quoted Dr Allan Ropper, Chair of Neurology at Tufts University Medical School, who said: *the historical archives say that FDR could move one leg on a given day and not the next, which argues against Guillain-Barré. What's more adults were stricken by polio in the 1920s, even though most cases were children ... fever is indicative of polio and not of Guillain-Barré.* Dr Lauro Halstead said he is not convinced by this new theory. Although the two illnesses share some symptoms, according to Halstead the onset of FDR's illness sounds like polio. He said that with Guillain-Barré, *recovery is sort of the rule. Most (though not all) folks recover quite nicely.* (*HealthDayNews* 30/10/03) Dr Dalakas, head of the Neuromuscular Diseases Section at the National Institute of Neurological Diseases and Stroke, USA, was quoted in the *LA Times* (31/10/03): *I think it's a significant stretch ... Roosevelt's fever and other factors would strongly indicate polio, and contracting polio at Roosevelt's age would be unusual but not unique.* In any case FDR's diagnosis of polio, whether correct or not, was to result in millions not contracting polio. FDR helped found the March of Dimes that hired Dr Salk to work on a vaccine against polio.

How polio shapes survivors' world views

Rhoda Olkin is an American psychologist who had polio. You may have read the chapters on psychosocial dimensions of polio and post-polio that she contributed to the book, *Managing Post-Polio* edited by Dr Lauro Halstead. Olkin has also written an excellent book, *What psychotherapists should know about disability* (published by Guilford Press, 1999). There she talks about ways in which having polio has changed her world view. Having a *disability often forces an admission of personal vulnerability, an appreciation of how random events can happen to a person, and an altered relationship to probabilities.* Olkin tells how she contracted polio in 1954, one of two isolated cases in the state of Michigan. *A random event had happened to me. The occurrence of this event, the fact of its having happened, was a lesson to me: I learnt that lightning can strike and having learnt that could not unlearn it. This knowledge influenced how I viewed subsequent events. For instance, I was worried about having amniocentesis during pregnancy because of the risk of miscarriage. I was assured that the risk was low and was cited statistics, which I didn't find in the least bit reassuring. Why not? Because in 1954 only two people in the state of Michigan contracted polio, and I was one of them — those odds were minuscule, but they happened. It was a lesson to me in another way; I knew that many other people had not learned that lightning could strike them, and I both envied and disliked them for this. And in an odd way I felt I had special knowledge and prized this specialness ... the fact of disability often forces an admission of personal vulnerability, an appreciation of how random events can happen to a person, and an altered relationship to probabilities.*

New book on Sister Kenny

Central Queensland University has recently published a 227 page book, *Sister Elizabeth Kenny: Maverick heroine of the polio treatment controversy*, by Wade Alexander. The author is an American polio survivor who attributes his *almost complete recovery to my mother's very early application of Kenny's method during the acute stage of the disease*. In 1994 Alexander visited Australia to attend a conference and used the opportunity to discover what he could about Kenny. He found most Australians had never heard of her so he became determined to write her story: *How she grew up in Australia to become an exceptional woman, a nurse and a healer; developed a treatment for polio that helped many of its victims; and how she fought for it*. In the epilogue Alexander refers to Dr Robert Bingham's research of US army personnel during World War II which was published in the *Journal of Bone and Joint Surgery* in 1949. In this early identification of the late effects of polio Bingham described a *neuromuscular syndrome* that he had observed in 264 servicemen who complained of excessive pain and fatigue during training. Bingham found these men had mild deformities, moderate muscle weakness and occasional muscle atrophy. He coined the name *fibrodystrophy* for the condition and wrote that its etiology *is presumed to be abortive or non-paralytic attacks of anterior poliomyelitis during the patient's infancy or childhood*. The book sells for \$29.95 and can also be purchased by sending a cheque for \$31.00 payable to *Sister Kenny Committee* to Lorna Rickert, "Pine Lodge", 376 Rickerts Road, Mail Service 223, Nobby, Qld, 4360 (this covers postage). Interestingly although the author is American the book is currently not available on the US online bookstores.

Transforming lives of polio survivors in Madras

Millions of Indian people with mobility disabilities, many of them polio survivors, get around by using crutches, using improvised aids such as a platform on wheels or by dragging themselves along the ground. According to a BBC report (25/2/03) it is rare to see a self-driven wheelchair in India. Three years ago Elizabeth Herridge, the wife of the UK deputy high commissioner in Madras, started teaching English at a school for disabled children. Since then she has started a scheme for wheelchairs to be shipped to India by British Aerospace Systems. Elizabeth says: *It started with one small boy here, who took half an hour to crawl down the wheelchair ramp to my class and I thought, we can do better than this, we can get him a wheelchair. Then I realized NOBODY had wheelchairs*. Visiting the UK she heard of a charity that runs community workshops in prisons. She asked for a hundred wheelchairs. *The inmates at the high-security Garth prison, in Lancashire, swung into action. To date, they have renovated 350 wheelchairs for Madras – each one tailor-made for a specific adult or child, their size and requirements ... One of the adult recipients is Selvi, a polio patient in her late 30s who teaches at the school. All she had in the past is occasional use of a shared wheelchair pushed by someone else. 'I'll be able to move without any help now. I'll also be able to help the younger children, take them on my lap and wheel them around ... And I can fold the wheelchair and take it on the train when I visit my home town'. The big hurdle now is to make India more wheelchair-friendly. Ramps are almost unheard of and pavements are appalling*.

Can You Help to Spread the Word?

If you can help to get the message out about the late effects of polio by putting Network pamphlets on display in, for example, pharmacies, doctors' surgeries or waiting rooms, clinics, shopping centre notice boards, libraries and community health centres, please contact Alice (02 9747 4694) and she will post some out to you.

Support Group News

Neil von Schill

Support Group Co-ordinator

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In August I visited **Peter Whelan** who lives at Lilli Pilli near **Batemans Bay** and he is keen to start a Support Group which will service that area. If you live within the area and would like to have contact with other polio survivors I know that Peter would love to hear from you. He can be contacted on **02 4471 2635**. Give him a call.

During the Dubbo Conference a number of members indicated a willingness to expand the effectiveness of the Network in country areas. To this end I recently made a couple of trips to further this interest.

Early in October I travelled to **Condobolin** to visit **Bill and Ruth Worthington** where I was made most welcome. Bill has agreed to be a Convenor and we will look to holding an inaugural meeting sometime in the new year. If you live in the area Bill can be contacted on **02 6895 2870**.

In November I was on the road again to see **Peter and Heather Drady** who live at Lyndhurst. Peter has undertaken to be our **Regional Representative** for the **Blayney/Cowra** area. His phone number is **02 6367 5095**. Following a beautiful morning tea and lunch I travelled on to **Wagga Wagga** where I called on **Isabelle and Clarrie Thompson**. They are keen to assist in the formation of a Support Group in the Wagga Wagga area. We hope to establish a group there by mid next year. Isabelle has agreed to be the Convenor and her contact number is **02 6926 2459**.

Another member at the Dubbo Conference who indicated a willingness to further his contribution to the Network is **Terry Bell** from **Moree** in the north west of the state. Terry was an enthusiastic participant who thoroughly enjoyed his experiences in Dubbo (*Ed. See Terry's letter on page 15*). He has undertaken to become our **Regional Representative** for the **North West Slopes and Plains**. He can be contacted by phoning the **National Relay Service** on **13 36 77** and asking to be connected to him on **02 6751 1554**.

Congratulations to **Pat Adamson** and the members in the **Port Macquarie** area for the enthusiastic manner in which they embraced the formation of a Support Group in their area. Convenor Pat (**02 6581 3704**) held a very successful inaugural meeting on 7 November with 21 people in attendance. Their next meeting is on **8 February 2004**.

On 27 November we took the first steps in establishing a Support Group in the **Marrickville** area. We have the core of what I believe will be a viable group and I am delighted to announce that **Maura Outterside** has undertaken to convene the Group. The next meeting will be held at 2:00 pm on Thursday **5 February 2004** at Petersham RSL Club. If you are interested in attending please contact Maura on **02 9718 5803**.

Finally, the foundation Convenor of the **Northern Beaches** Support Group, **Elizabeth Woods**, has reluctantly had to relinquish her position because of family commitments. We thank Elizabeth for her efforts in helping establish the Group and her dedication to assisting others. If there is a member who wants to ensure that the Group continues to operate, please contact me on 02 6025 6169 as soon as possible.

May I take this opportunity of wishing Convenors and Regional Representatives and indeed all Network members a very Merry Christmas and a happy and healthy New Year.

Post-Polio Post



One of our regular correspondents, member Lynne Ellis from the Central Coast, writes about her experiences as a mother with a physical disability.

In a recent *Network News* [Issue 59, August 2003, *Being a parent with polio*] there was something about polio parents, or the children of same ... were they disadvantaged or not?

I don't think mine were, although as you know, there are a lot of things I cannot do. For instance, I can't run after toddlers who might run away. But when my two first started to "toddle" Stan drilled into them that they must NEVER run away from mummy. And do you know they never did. They knew that lightening would strike if they did! In fact a 20 months old Kim was quite surprised to find a woman who ran after him ... he didn't think women could run !

The kids always instinctively helped me down gutters or steps and carried things for me etc. People used to marvel at how considerate they were. They were brought up to help people and they are now helpful considerate adults.

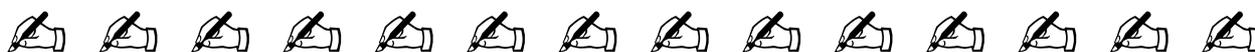
They both say that they think having a disabled mother has made them better, more understanding people and don't feel that it did them any harm.

Member Terry Bell, Regional Representative for the Moree area, writes of the impact on him of the Network's regional Conference held in Dubbo in September.

This Conference was my first, but hopefully not my last, as the information that I received and companionship that I experienced was so uplifting I came home fairly well floating on the euphoria.

The fact that I was in the presence of so many people likewise affected by polio (even though I knew you were all out there) eased my mind no end.

To those people who could not attend the Conference, if you can somehow arrange to view the video that was shown, "*The Epidemic – I don't remember anything but I'll never forget*", I thoroughly recommend it as compulsory viewing for anyone who has pps, or is a carer or an associated health professional. The recollections of the family, nurses and others really brought home to me how lucky I have been to be relatively "normal" for most of my life, and yet how far I have come from the severe onset of pps. This reinforces the need to live day by day, hour by hour, and to appreciate the little things in life and what our carers and loved ones do and give to us.



**The Management Committee wishes
every member and friend a
Happy and Holy Christmas
and a
Healthy and Peaceful New Year**



Post-Polio Network Seminar Program 2004

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|---------------------------------|---|--|
| Saturday 6 March | Northcott Society 1 Fennell Street Parramatta | The Feldenkreis Method presented by Zoran Kovich MSc <i>Full details will appear in the next issue of Network News</i> |
| Saturday 19 June | Kogarah (venue to be advised) | Seminar presented by Sailors with Disabilities <i>Further details will be in upcoming issues of Network News</i> |
| Tuesday 31 August | Northcott Society 1 Fennell Street Parramatta | Seminar presented by Dr Marcia Falconer <i>Further details will be in upcoming issues of Network News</i> |
| Saturday 27 November | Ryde (venue to be advised) | Sixteenth Annual General Meeting followed by a Seminar <i>Further details will be in upcoming issues of Network News</i> |

Network Volunteers – Who Does What

| | | | |
|-------------------|--|------------------------------------|--------------|
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| Anne Buchanan | <i>Information Bulletin</i> | bulletin@post-polionetwork.org.au | 02 9771 2748 |
| George Laszuk | Advocacy & Support | advocacy@post-polionetwork.org.au | 0412 082 983 |
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