President's Corner

You will find the Network’s 1998/1999 Annual Report enclosed. This is your last reminder that our Annual General Meeting and Seminar will be held on Saturday 30 October at the Independent Living Centre, 600 Victoria Road, Ryde, commencing at 11:00 am. Please be there if you can. There is an hour’s break for lunch between the AGM and the Seminar, so if you find it hard to sit in one place for too long you will have ample opportunity to get your muscles and joints moving. Please bring your own lunch - tea, coffee and juice will be provided. Our guest speaker is Elizabeth Dean who has travelled from Canada to be with us. In 1996 Elizabeth was a keynote speaker at the Network’s Conference Living with the Late Effects of Polio and we hope that she will be warmly welcomed back to Australia by a full house. During the Seminar Elizabeth will also be launching the Network’s new booklet Helping Polio Survivors Live Successfully with the Late Effects of Polio. Full details are on page 2. All members will receive a free copy of the booklet - come along to the AGM and receive yours at the launch.

Post-Polio Awareness Week is just around the corner, 1 - 7 November. A colourful poster which promotes the Network and raises community awareness of the late effects of polio is included with this Newsletter. We need your help to distribute the poster and would greatly appreciate you (or a friend) putting it up somewhere in your local community such as a pharmacy, doctor’s waiting room, clinic, notice board, library or community health centre etc. If you are able to distribute extra posters, please ring Alice on (02) 9747 4694. There are still so many people who have never heard of the late effects of polio or the Network – as they age it is more important to contact them.

Our Tenth Anniversary Luncheon will be held on Saturday 6 November 1999 from 11:00 am, at the Regency Function Centre, Burwood RSL Club, 96 Shaftesbury Road, Burwood. We are very proud to reach our tenth birthday and want to celebrate the day with as many members and friends as possible – please try to come along. The cost is only $35 for a three-course meal, and includes soft drink. Our guest speaker is retired Magistrate Barbara Holborow who promises an informative and entertaining afternoon. Please send your form back as soon as you can.

As if the celebratory luncheon itself is not incentive enough, the Raffle will also be drawn on 6 November. As an unfunded organisation, we have to fund-raise in order to provide the extensive Network services we do, and to enable us to outreach to polio survivors in rural and remote areas. Sales of tickets have been proceeding well, but there are still outstanding raffle books to be returned. Please send back ticket butts (and unsold tickets) with your money as soon as possible.

The last Newsletter for the year will be sent out in December. The Seminar dates for 1999 will be advised in that issue, together with details of the new Management Committee elected at the AGM.

Some members with failing eye-sight would like to receive the Newsletter on an audio tape. If you wish to receive the Newsletter in this format, or are able to read it onto tape, please contact me.

The Committee and I are looking forward to catching up with friends and meeting new members at the AGM. Don’t forget to bring a plate for afternoon tea to help celebrate an early Christmas.

Unless otherwise stated, the articles in this Newsletter may be reprinted provided that they are reproduced in full (including any references) and the author, the source and the Post-Polio Network (NSW) Inc are acknowledged in full. Articles may not be edited or summarised without the prior written approval of the Network. The views expressed in this publication are not necessarily those of the Network, and any products, services or treatments described are not necessarily endorsed or recommended by the Network.
Annual General Meeting and Seminar

Date: Saturday, 30 October 1999
Time: 11:00 am - 12:00 pm (lunch break 12:00 - 1:00 pm)
Bring a packed lunch to eat from 12:00 noon and catch up with friends before the Seminar, and afterwards at afternoon tea. As usual, fruit juice, tea and coffee will be provided.

Venue: The Independent Living Centre
600 Victoria Road, Ryde
Parking is available on the premises. It would be appreciated if those who are more mobile would leave the closer parking for members who are only able to walk or wheel short distances.

The Annual General Meeting is your chance to have a say in the running of the Network - please be there if you can.

Dr Elizabeth Dean [Associate Professor, School of Rehabilitation Sciences, University of British Columbia, Canada] who was a keynote speaker at the Network's Conference Living with the Late Effects of Polio in 1996, is our guest speaker following the lunch break. Elizabeth is a physiotherapist who has conducted extensive research into the management of fatigue, weakness and reduced endurance resulting from the late effects of polio, and has published and spoken internationally on these topics. She has also investigated respiratory problems, exercise programs and the use of aids.

Elizabeth's presentation is entitled Empowering the Polio Survivor: A Key to the Management of the Late Effects of the Disease. Come along and learn from Elizabeth's extensive experience and practical approach to the management of post-polio problems.

Following Elizabeth's presentation she will officially launch our new booklet Helping Polio Survivors Live Successfully with the Late Effects of Polio. This 12-page booklet has been a major project of the Management Committee this year and was developed to provide a quick yet comprehensive source of information on the late effects of polio, and on the benefits of Network membership. Thanks go to Dr Mary Westbrook who took on the Herculean task of pulling together everyone's views and writing the final very professional product. The booklet will be sent out to all people who enquire about the Network, and we hope it will encourage more people to join. All existing members will also receive one free copy, and extra copies will be available for sale. Come along to the AGM/Seminar and get your copy there.

If this is the first Seminar you have attended, please introduce yourself to a Committee member. We look forward to seeing everyone there.
CONNECTING WITH OUR POLIO HISTORY:
THE NORTHCOTT SOCIETY'S 70th BIRTHDAY CELEBRATIONS

Mary Westbrook

I have just read The Grit Behind the Miracle (1). This book tells the story of an emergency hospital that was converted from a summer camp in Hickory, North Carolina to cope with a polio epidemic in 1944. The book begins with the announcement that a 50th year picnic reunion is to be held for former patients at which they will be asked to share their hospital memories and subsequent life experiences. Part of the book consists of their stories, some of which end, of course, with the late effects of polio. The book reminded me of my year in the Royal Alexandra Hospital for Children both at Camperdown and Collaroy. I now know no one who shared my experiences of that year. There is no one to reminisce with about when we stole plaster bandages from the physiotherapy room and put our dolls in plaster, used rulers to scratch under the plaster casts of fellow patients who were itchy (particularly after being in the sun all morning), or endured sad and terrible happenings. One of the most inconvenient things about women friends is that they change their surnames when they marry making it hard to maintain contact. I often wonder if any inmates of RAHC in 1949-50 belong to the Network. Perhaps we meet at seminars and don't realise that we share a history. Janey Olsen, Jannie Glencross, Gloria Honeycott (Honey Bee), Joy Ironmonger, Judy Reidy, Paddy Brooks, Elaine Gibbons, Mary (was it Brown? your home was near Central Station) are you out there somewhere? What has happened in your lives?

Members of the Post-Polio Network will have an opportunity to catch up with old acquaintances as we have all received an invitation to help celebrate the Northcott Society's 70th birthday. This organisation has played an important role in the lives of polio survivors in NSW. Many received direct services from the NSW Crippled Children's Society (Northcott's name until 1993) and some still have their boots and orthotics made there. Other survivors have been affected indirectly through the Society's role in changing community attitudes toward the treatment of children with disabilities (2,3). Today the Northcott Society provides support for the Post-Polio Network through the production of our Newsletter and the loan of its premises for seminars. A copy of the invitation is printed on page 5. Come along and catch up with your past!

Some of you may be unaware of how the Society began or how much it has changed since the days of the polio epidemics. The Society for Crippled Children was established in 1929 by the Rotary Club of Sydney in an attempt to provide medical care, education and vocational training for children with physical disabilities. Initially these children needed to be identified. Records were not available so a doorknock survey was conducted. Not infrequently, Rotarians encountered slammed doors as the stigma of having a disabled child resulted in "hundreds of crippled children living out a lonely, obscure life in back rooms of their homes ... children for whom no constructive rehabilitation was then available" (2). Margaret Watts, the first Welfare Officer of the Society, wrote that in those days, "Aftercare following hospitalisation was impossible, as there was nowhere for children to go. Holiday care in suitable homes was practically non-existent. In the public hospitals there were few orthopaedic beds. There was no organised service for conveying home-bound children or those in heavy appliances, to and from hospital. And at that time there were no schools, other than the Fred Birks Activity School at the Royal Alexandra Hospital, for crippled children to attend" (2). The Women's Auxiliaries, to which some of our mothers belonged, were important fundraisers for the Society. Some Auxiliary workers assisted Mrs Watts in her country work. In one small town they learned of a severely
disabled child of eight who lived in a valley which was reached by a perilous winding track. They arrived at a desolate farmhouse with earth floors. "Six dogs yelped furiously and the crippled boy, a polio case came hobbling towards them ... It turned out the mother had ‘dropped her bundle’ because she felt that life was quite hopeless but the visit gave her new heart. She undertook to bring the handicapped boy to the Society’s next orthopaedic clinic at Wollongong. Two months later, he entered Margaret Reid Hospital and made a reasonably good recovery" (2).

The Society was to open three hospitals, six special schools, and five sheltered workshops. Today all these institutions have been closed. This can be seen as a reaction to the Disability Rights movement, in which many polio survivors, for example, Elizabeth Hastings, were involved. Its effects on community attitudes are enshrined in legislation such as the Disability Services Act (1986) which established principles and objectives for the provision and funding of disability services which were based on a philosophy of rights, dignity and accountability. The Disability Discrimination Act passed in 1992, made it unlawful to discriminate on the basis of disability in areas such as education, employment, accommodation, access to premises, finance, provision of goods and services, activities of clubs, and the administration of Commonwealth laws and programs. The Society responded more swiftly than did many organisations. It changed its name despite predictions (possibly correct) that the new name would elicit less pity and hence fewer donations. Announcing this change in 1993, the Society said “We’re not crippled anymore. Crippled is just too limiting a word when we focus on abilities and achievements” (3).

Today the 23 services that Northcott provides for children and adults with disabilities and their families include Early Intervention programs, Recreation, and Respite services for children, Jobmatch and Post-School Options programs, Computer Assistive Technology and Equipment services. An example of outreach services is the weekends that are held from time to time for mothers of children with disabilities, for fathers, for siblings and for the children themselves. Participants relax in an enjoyable setting, make supportive friendships and explore solutions for problems they share. These weekends are always overbooked and like most Northcott services could be provided for many more if funds were available. Today the Society’s only accommodation services are at Beverley Park, Woodbine (a house for adolescents), and the Merrylands Independent Living units where people live for a period while acquiring skills and confidence to move into the community. The Society’s rural services are situated in the Central West, the North Coast, the Riverina and New England regions. Northcott consumers participate on its advisory and staff selection committees and in policy development and service reviews. Currently three of the ten directors on the Board of the Society have disabilities. Two are polio survivors. In a recent Annual Report Glenn Gardner, CEO of Northcott, wrote that “More and more services are expected to be community based and designed to maintain people with disabilities in the widest possible context of Australian society. The Northcott Society continues to demonstrate a high level of commitment to this philosophy” (3).

References

INVIATION FROM THE NORTHCOTT SOCIETY

An invitation is extended to members of the Post-Polio Network to celebrate our 70th Anniversary at our AGM and reception to be held at The Sydney Town Hall on Tuesday, 16 November, commencing at 3 pm. Present will be our Patron and State Governor, the Hon Gordon Samuels AC and Mrs Samuels.

In holding the event at The Sydney Town Hall, we will be returning to the site of the meeting on 17 December 1929 which saw the establishment of the NSW Society for Crippled Children.

We hope as many of you as possible will be able to be with us on this very special occasion. As this year is the International Year of Older persons, the event also provides us with the opportunity to honour and acknowledge all those who have contributed to our success over the years.

Disabled access to The Sydney Town Hall is via the Druitt Street Entrance. Full details regarding disabled parking will be provided to those attending the event.

If you wish to attend you MUST contact
Erica Aronsten on (02) 9890 0132
NO LATER THAN 2 NOVEMBER

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This Conference, hosted by Polio Network Victoria, will be held at the Edmund Barton Centre, South Road, Moorabbin, Victoria. The Conference is to be held from Wednesday 19 January to Friday 21 January (for people who have had polio, their families, carers and health professionals) and on Saturday 22 January 2000 (for health professionals only).

Conference Registration Packages will soon be sent to everyone who completed an Expression of Interest Form. The Network will have copies of the Package available at the Annual General Meeting and at the Tenth Anniversary Luncheon. The finalised costs are:

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<tr>
<th>Package Description</th>
<th>Cost</th>
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<tr>
<td>Conference registration, all meals including the Conference Dinner, and Conference papers, but not including accommodation</td>
<td>$250.00</td>
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<tr>
<td>Conference registration, accommodation and all meals including the Conference Dinner, and Conference papers (early bird registration – required by 30 November 1999)</td>
<td>$475.00</td>
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<tr>
<td>Conference registration, accommodation and all meals including the Conference Dinner, and Conference papers (for registrations received after 30 November 1999)</td>
<td>$525.00</td>
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Health professionals who attend on 22 January 2000 will pay $150 which includes full registration and meals. All health professionals should be encouraged to attend.

Jeannette Marshall from Polio Network Victoria has advised that the number of registrants at the Conference will be restricted to around 200, to ensure that everyone can be comfortably accommodated, especially in the dining facilities. If you are planning to attend, don’t delay once you receive your Registration Package. This is the first International Conference held in Australia since 1996 and you are encouraged to attend if you can.
SCALING THE WALL

Millie Malone

Millie Malone is an American polio survivor who hits the nail on the head with the following article. Millie has kindly given us permission to reprint the piece, which was written for and first published in Gleanings, the Newsletter of the Nebraska Polio Survivors Association.

You can't do it. You cannot scale the wall. I'm talking about the infamous Polio Wall. You know the one. The one that you hit when you overdo. That's the one, all right. You know the drill. You bop along, feeling fine, thinking that you can do another hour's worth of whatever activity you are doing, even though you know you might be pushing it. Then, all of a sudden, there it is. The wall. It looms large. You are totally out of strength, with no energy to go another step.

What do you do when you "hit the wall"? My friend, you crash, that is what you do. You may pay for not being aware of that wall with a few days in bed. Perhaps you will be lucky and be able to remain somewhat vertical, though sadly out of plumb, but pay you will. In my own case, I will stagger around for a few days in a zombie like state, hurting all over, ears ringing, and incoherent. Rather a high price to pay for another hour's worth of shopping, or missing a couple of hours of sleep, or any of a multitude of things that can trip the trigger that pops that wall up in front of me.

Why do we do it? There is a theory that all polio survivors have Type A personalities. Some people think that we strove so hard to overcome the original virus and its aftermath that we cannot now slow down. I don't know. I know that any sensible able-bodied person will stop when he is tired. He will call in sick if he is sick. Not your basic polio, though. Nope. Can't be thought wimpy, must keep up with the pack.

Actually, we must be ahead of the pack to be truly comfortable. Comfortable being a relative term, that is. Comfortably aching in every muscle, comfortably goggly and unable to think straight. But if we slowed down, people might think we are "crippled" or in some way not as capable as our coworkers. We must outstrip everyone else. It is the Polio Rule.

The Rule must change. We are wearing out our remaining motor neurons when we overdo. We must learn to "Conserve to Preserve". If we want any quality of life, this is a lesson we must learn. I have heard it over and over again - "I am working as hard as I can to stay out of a wheelchair". However, if we do use a wheelchair, at least for the long distance things, we may well be able to walk around our houses longer. I use the motorized carts whenever possible for shopping. It makes the difference between being able to go into one store and then drag my weary body home or being able to spend a couple of hours, leisurely browsing through all the items on display and returning home with enough strength left over to get back into the house.

It is so hard to "give in". To allow ourselves to use the aids that we need, such as canes, walkers and wheelchairs. Why? No one thinks you are being a wimp if you drive your car to the store. It's too far to walk, so you drive. If it is too far for you to walk around the mall, why not use a chair? It is merely a tool, after all, just as your car is. I think we don't want to return to the days when we were struggling to get out of the braces, throw away the crutches, ditch that wheelchair. We feel we have failed if we go back to using those aids again.

We have not failed. Most of us have struggled valiantly, have gotten an education, married, raised a family and did everything that an able-bodied person could do and, sometimes, a few things they couldn't do. It is no disgrace to use whatever tool it takes to enjoy the rest of our lives. If using a wheelchair conserves enough energy for us to be able to go to a ball game with our grandchildren, where is the harm?

Let's slow down, smell the roses, go slow enough to enjoy the view, and make our bodies last just a little bit longer. We have earned this, we deserve it, and we should not be ashamed to do it.
THE TEN COMMANDMENTS OF POST-POLIO SEQUELAE

Dr Richard L Bruno
Chairperson, International Post-Polio Task Force, and
Director, The Post-Polio Institute, Englewood Hospital and Medical Center, Englewood, New Jersey USA

Dr Nancy M Frick
Executive Director, Harvest Center Inc, and Director of Education, International Post-Polio Task Force

The following article was published in New Mobility in June 1999 and Dr Bruno and Dr Frick have kindly made it available to polio survivors through their Web site <http://members.aol.com/harvestctr/pps/lib.html>. Here you can access a PPS Library which includes all of their papers describing their research and treatment of PPS.

After 15 years of searching, archaeologists from The Post-Polio Institute have unearthed the "commandments" for treating Post-Polio Sequelae (PPS) ...

1 Listen to Yourself!

Polio survivors often turned themselves off from the neck down after they got polio. The first step in treating PPS is to listen to yourself: to what you feel, physically and emotionally, when you feel it and why. Our most powerful tool in treating PPS is the daily logs our patients keep that relate activities to their symptoms. However, polio survivors sometimes listen too much: to vitamin salesmen saying some herb or spice will "cure" PPS, to other polio survivors who warn that you will eventually have every possible PPS symptom, and to friends and family members (and the voices in your own head) saying you're lazy and that you must "use it or lose it". Polio survivors need to listen to their own bodies, not to busybodies.

2 Activity is Not Exercise!

Polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs, their muscle weakness will go away. The opposite is true: the more you overuse your muscles the more strength you lose. Muscles affected by polio lost at least 60% of their motor neurons; even limbs you thought were not affected by polio lost about 40%. Most disturbing is that polio survivors with new muscle weakness lose on average 7% of their motor neurons per year, while survivors with severe weakness can lose up to 50% per year! You need to substitute a "conserve it to preserve it" lifestyle for the "use it or lose it" philosophy. Stretching may help pain and non-fatiguing exercise for specific muscles can prevent you from losing the strength you have after you get a brace. But polio survivors need to work smarter, not harder.

3 Brake, Don't Break

The follow-up study of our patients showed that taking two 15 minutes rest breaks per day - that's doing absolutely nothing for 15 minutes - was the single most effective treatment for PPS symptoms. Another study showed that polio survivors who paced activity -- that is worked and then rested for an equal amount of time -- could do 240 percent more work than if they pushed straight through. Our patients who took rest breaks, paced activities and conserved energy had up to 22% less pain, weakness and fatigue. But polio survivors who quit or refused therapy had 21% more fatigue and 76% more weakness. For polio survivors, slow and steady wins the race.
4 A Crutch is Not a Crutch ...

... and a brace is not a sign of failure or of “giving up”. You use three times less energy (and look better walking) using a short leg brace on a weakened leg. Overworked muscles and joints hurt and nerves die after decades of doing too much work with too few motor neurons. So why not use a brace, cane, crutches (dare we say a wheelchair or a scooter) if they decrease your symptoms and make it possible to finally take that trip to Disney World? We know, you’ll slow down and take care of yourself “when you’re ready”. And you’ll use a wheelchair “when there’s no other choice”. Well, you don’t drive your car until it’s out of gas. Why drive your body until it’s out of neurons?

5 Just Say “No” to drugs, unless ...

Five studies have failed to find that any drug that treat PPS. And there have been no studies showing that herbal remedies or magnets reduce symptoms. Polio survivors shouldn’t think that they can run themselves ragged, apply a magnet or pop a pill, and their PPS will disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done! Masking symptoms -- with magnets or morphine -- will not cure PPS. However, two studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medication for a longer time after surgery or an injury (see 10 below).

6 Sleep Right, All Night

The majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders, such sleep apnea (not breathing) or muscles twitching and jumping all over your body during the night. However, polio survivors are usually not aware that they stop breathing or twitch! You need a sleep study if you awaken at night with your heart pounding, anxiety, shortness of breath, choking, twitching, or awaken in the morning with a headache or not feeling rested. “Post-polio fatigue” may be due to a treatable sleep disorder.

7 Some Polio Survivors Like it Hot

Polio survivors have cold and purple “polio feet” because the nerves that control the size of blood vessels were killed by the poliovirus. Actually, polio survivors’ nerves and muscles function as if it’s 20 degrees colder than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of the silk-like plastic fiber polypropylene (sold as GORTEX or THINSULATE) that holds in your body heat.

8 Breakfast Is the Most Important Meal of the Day

For once Mom was right. Many polio survivors eat a Type A diet: no breakfast, coffee for lunch and cold pizza for dinner. A recent study shows that the less protein polio survivors have at breakfast the more severe their fatigue and muscle weakness during the day. When our patients follow a hypoglycemia diet (have 16 grams of low-fat protein at breakfast and small, non-carbohydrate snacks throughout the day) they have a remarkable reduction in fatigue. Protein in the morning does stop your mid-day yawning.

9 Do Unto Yourself as You Have Been Doing For Others

Many polio survivors were verbally abused, slapped or even beaten by therapists or family members when they had polio to “motivate” them to get up and walk. So polio survivors
took control, becoming Type A super-achievers, “the best and the brightest”, doing everything for everyone except themselves. Many polio survivors do for others and don’t ask for help because they are afraid of being abused again. Isn’t it time that you got something back for all you’ve done for others? Accepting assistance is not the same as being dependent. Accepting assistance can keep you independent. But appearing “disabled”, by not doing for others, asking for help or using a scooter, will be frightening. Remember: If you don’t feel guilty or anxious you are not taking care of yourself and managing your PPS.

10 Make Doctors Cooperate Before They Operate

Polio survivors are easily anesthetized because the part of the brain that keeps them awake was damaged by the poliovirus. Polio survivors also stay anesthetized longer and can have breathing trouble with anesthesia. Even nerve blocks using local anesthetics can cause problems. All polio survivors should have lung function tests before having a general anesthetic. Your complete polio history and any new problems with breathing, sleeping and swallowing should be brought to the attention of your surgeon or dentist - and especially your anesthesiologist - long before you go under the knife. Polio survivors should NEVER have same-day surgery or outpatient tests (like an endoscopy) that require an anesthetic.

The Golden Rule for Polio Survivors

If anything causes fatigue, weakness, or pain, Don't Do It!
(or do a lot less of it)

... and...

The Golden Rule for Polio Survivors’ Friends and Family

See no evil, hear no evil . . . and help only when asked

Polio survivors have spent their lives trying to look and act “normal”. Using a brace they discarded 30 years ago and reducing their super-active daily schedule is both frightening and difficult for them to. So, friends and family need to be supportive of life-style changes and accept survivors’ physical limitations and new assistive devices. Most important, friends and family need to be willing to do the physical tasks a polio survivor should not do, but only when the polio survivor asks. Friends and family need to know everything about PPS but say nothing: neither gentle reminders nor well-meaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. Polio survivors must take responsibility for taking care of themselves and ask for help when they need it.

Help the Network by Buying a PPN Badge

The Network now has for sale a four-colour enamelled badge depicting a single polio virus particle. The badge is 23 mm x 23 mm and the design (shown at left) is very striking. The badges cost $5 each and are suitable for men or women. Each badge comes with a description of the virus and information about the Network. Not only is the badge a great fashion statement, it is an innovative way to promote the Network and raise a little money to help its work. Order your badge today or buy one at the AGM.
HOW TO PREVENT FURTHER DISABILITY IN POLIO SURVIVORS

Julie K Silver MD

Julie K Silver MD is a medical doctor who specialises in physiatry. Dr Silver pursues her interests in musculoskeletal rehabilitation and Post-Polio Syndrome as the Medical Director of one of Spaulding Rehabilitation Hospital’s outpatient centres in Framingham, Massachusetts.

Dr Silver teaches at Harvard Medical School and just recently completed a book titled Preventing Further Disability in Polio Survivors that will be available from Yale University Press in early 2000.

This article was first published in Accent on Living, Summer 1999, and is reprinted here with the gracious permission of the author.

The thought of becoming increasingly disabled as aging progresses is something we all fear. For polio survivors, particularly those who are experiencing symptoms of Post-Polio Syndrome (PPS), the fear of not knowing what the future will bring may be overwhelming.

Although it is important to treat the symptoms of PPS, there are many other reasons why polio survivors may become further disabled. This article addresses three major reasons why polio survivors may experience further disability as they age, and how to prevent this from occurring.

SYSTEMATICALLY ADDRESSING AND TREATING ALL POTENTIALLY SERIOUS MEDICAL CONDITIONS

The symptoms of PPS (i.e.: new weakness, fatigue, pain, cold intolerance, breathing and swallowing problems, and muscle atrophy) may occur with many diseases as well as with a prior history of polio. Moreover, some of these "other" diseases may be life-threatening whereas PPS generally is not. Therefore, anyone experiencing symptoms consistent with PPS should have a thorough work-up by a physician who is a polio expert in order to eliminate other, more serious or potentially curable medical conditions that may mimic symptoms found with PPS. If all other diseases are ruled out and the diagnosis of PPS is made, polio survivors should remain alert to the onset of new symptoms or the worsening of previous symptoms. A re-evaluation is indicated with either of these scenarios in order not to mistake the onset of a new medical condition for PPS.

For instance, if a polio survivor has a long history of muscle pain in his arms and legs and is now experiencing abdominal pain, this warrants investigation. New abdominal pain may be a minor problem involving constipation or may herald the first warning signs of a life-threatening condition such as colon cancer. Therefore, despite having had a thorough evaluation by a polio doctor and being diagnosed with PPS, any individual experiencing new problems or more severe problems than initially reported, should be re-evaluated.

Although PPS rarely becomes life-threatening, there are many other medical conditions that may seem like minor annoyances at first, but can escalate into disabling or even deadly diseases. Some common diseases that are frequently underestimated include high blood pressure (hypertension), high cholesterol levels (hypercholestremia), and poorly controlled blood sugar (diabetes).

These are examples of diseases that should be aggressively treated in order to prevent severely disabling and potentially life threatening events such as a stroke.
Polio web sites and newsletters across the country have often contained information about medications that may exacerbate the symptoms of PPS. While this is an extremely important topic, it is imperative the polio survivors don’t recklessly abandon medications they are taking to control a variety of other serious medical conditions.

Anyone who is concerned with possible drug interactions or side effects from a medication should discuss this with the prescribing physician who then has the opportunity to consider alternate treatment approaches. Certainly the goal is always to have individuals take only those medications that work effectively and cause few side effects; however, in reality this is not always possible. As with all medical treatment, it is ultimately up to the individual taking the drug to decide whether the side effects are worth the benefits. The important point here is that polio survivors need to make informed decisions about which medications they will and won’t take. Medications used to treat disabling or potentially life threatening illnesses should not be discontinued even if they exacerbate the symptoms of PPS unless a reasonable alternative is available or unless the individual taking the medication fully understands what may happen without it and makes an informed decision not to use it regardless of the consequences.

PROTECTING THE ARMS

There is a direct correlation between the strength of an individual’s arms and their ability to care for themselves without assistance. Thus, one can say that the arms are the keys to independence and the stronger an individual’s arms are, the greater the likelihood that he or she will be independent. Think of it this way -- arms are essential for mobility (rising from a chair, transfers, etc), dressing, bathing, driving a car or even communicating by phone, fax or internet. While it is true that technology is providing new types of adaptive equipment that will enable individuals with upper extremity weakness to become more independent, keeping the arms strong and injury-free is essential.

Unfortunately protecting arms and avoiding injuries to them may be easier said than done - particularly in those individuals who rely on their arms to compensate for trunk or leg weakness. For instance, polio survivors who rely on their arms for mobility purposes are prone to having arm injuries such as rotator cuff problems in the shoulder, nerve injuries at the elbow or wrist, tendinitis and even muscle strains and ligament sprains.

For example, a polio survivor who uses a cane to walk puts pressure on the hand and arm that holds the cane. Further overuse of the arm holding the cane is very common due to putting pressure on it repeatedly in order to rise from chairs and the commodes.

The combination of using the arm during ambulation and transfers as well as for everyday activities may prove to be too much and an injury or new weakness can result. Studies have shown those polio survivors, who use wheelchairs or other assistive devices such as canes and crutches have higher than average risk of injuries to the arms.

Although injuries to the arms may be inevitable, early medical attention can do a lot to mitigate these injuries. On the other hand, ignoring pain, tenderness, swelling, numbness or tingling in the arms and hands can lead to serious permanent injuries, which may in turn lead to further disability. This is because injuries are nearly always easier to treat in the early stages and those injuries that are allowed to progress to a more advanced stage become much more difficult to cure.

The good news is that many, if not most, arm injuries are treatable and often curable. The cure may involve rest from activities that exacerbate the symptoms, splints, medications, injections, physical and/or occupational therapy, and in some cases even surgery. The earlier an injury is treated, regardless of the injury, the more likely that treatment will be successful.
In summary, for those polio survivors who have become accustomed to a variety of aches and pains, it is important to recognize that many of the symptoms that occur in the arms are treatable and potentially curable and, therefore, should not be ignored. Moreover, leaving injuries in the arms untreated may lead to significant disability that may be permanent.

**AVOIDING FALLS**

Falls resulting in serious injuries is one of the leading causes of disability in individuals as they age - regardless of whether they have a pre-existing disability. One of the most important things to remember about falls is that they are generally "preventable occurrences", rather than accidents.

Common injuries associated with falls include minor bruises and abrasions, broken bones, and head trauma that may lead to permanent brain damage. Obviously, all of these injuries can be potentially disabling. However, even if an individual simply has a fear of falling (without necessarily having experienced a fall with a serious injury) this may be equally disabling by leading to social isolation because they are afraid to go out. Therefore, regardless of whether an individual has fallen or is simply worried about falling in the future, this may significantly impact their quality of life.

Preventing falls is much easier to do when one understands how and why most falls occur. Certainly there are some absolutely unavoidable situations where preventing a fall would be virtually impossible, however, as noted above, most falls are avoidable with a little forethought and planning. Falls occur for a number of reasons, but in general they can be broken down into two categories.

- **The first category includes falls that occur due to a problem with the way an individual's body works.** This may be due to weakness, loss of balance, problems with vision or hearing, dizziness, etc.

- **The second category includes those falls that occur due to a problem with the environment.** This would include falls due to hazardous weather conditions, slippery floor surfaces, cluttered rooms, etc.

In order to prevent falls, both categories - your own body and your physical environment - should be carefully considered and changes made as deemed appropriate. Medical experts who specialize in treating polio survivors can be excellent resources for information on how to prevent falls as it applies to individual polio survivor. For instance, a polio doctor can determine whether new braces are needed, if physical therapy might improve balance and strength, etc. He can also recommend that a physical or occupational therapist visit your home or workplace in order to evaluate how to make the environment safer (and offer suggestions on how to protect your arms!). Polio doctors and other healthcare providers can offer invaluable advice on how to prevent falls and subsequent disability.

For those individuals who trip occasionally but haven't fallen (yet), it is important to remember that a trip is less than a step away from a fall. Anyone who is experiencing tripping or falling or who is concerned that they may fall, should seek medical attention. Most falls are preventable which means that serious injuries that lead to further disability in polio survivors can generally be prevented.

The three ways mentioned in this article to prevent further disability in polio survivors (treating all serious medical conditions, protecting the arms and preventing falls) are certainly not the only ways to prevent further disability, however, they are a good place to start. Moreover, polio survivors who take the initiative to try and prevent further disability will likely experience fewer problems in the future and in turn, this may give them a measure of comfort about what the future will bring.
A GOOD BOOK FOR POLIO SURVIVORS TO HAVE AT HAND

Mary Westbrook

GINI (Gazette International Networking Institute) in St Louis was one of the few polio-orientated organisations that did not forget the survivors of the polio epidemics after the introduction of the Salk and Sabin vaccines. GINI's name is a tribute to its founder, Gini (Virginia) Laurie, who has been described as one of the two grandmothers of the independent living movement. Gini's father was a doctor at St John's Hospital, St Louis. She recounted that, "In 1912, the year before I was born, four siblings were struck by polio: a 12 year old sister was mildly disabled, a 6 year old brother very seriously disabled, and two sisters, aged 3 and 9, died within days at St John's. In their memory my mother painted a mural on the ceiling of St John's chapel depicting them as angels. Sixteen years later I watched my significantly disabled brother die of pneumonia and underventilation at St John's. His funeral was at St John's chapel, underneath the mural of our sisters". Gini became a Red Cross volunteer in polio wards in the 1950s. In 1958 she began publication of Rehabilitation Gazette, a journal of news about how polio survivors managed at home. It has been described as the "glue that held the polios of the world together".

In 1979, polio survivor, Larry Schneider, wrote a letter to the Gazette describing the strange new symptoms of weakness, fatigue and pain that he was experiencing. Was he just becoming old early, asked Larry? Rehabilitation Gazette was inundated with letters from polios experiencing similar symptoms. GINI responded by holding the first ever conference on the late effects of polio in 1981. Further conferences have been held in St Louis every few years since then. The eighth will take place from 8-10 June 2000. These conferences have made St Louis a Mecca for polio survivors and quite a few Australians have attended a GINI conference. Many others subscribe to Polio Network News, which GINI has produced four times a year since 1985. In 1984 it also published the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors. Its 31 pages contained 55 entries on topics relevant to polio survivors. Now, 15 years later, GINI has revised and expanded the Handbook to take account of new understanding of polio's late effects based on research findings and the experiences of polio survivors and health practitioners. The new handbook has grown to 120 pages with 90 entries written by 40 experts from four countries. It is edited by Dr Frederick Maynard, a specialist in rehabilitation medicine and researcher into post-polio, and Joan Headley, a polio survivor, who has been executive director of GINI since Gini Laurie's death in 1989.

The new handbook is a most useful resource for any polio survivor. The topics, arranged from A to W, are diverse. They include descriptions of treatments you may be prescribed (for example: Medications, Exercise, Aquatic therapy, Alternative therapies, Occupational therapy, Orthopaedic surgery, Flu and Pneumococcal vaccines), assistive devices (for example: Ventilators, Braces, Orthotics, Adaptive equipment), tests you may be given (for example: EMG, Muscle biopsy, Pulmonary function tests), and problems polios are prone to and their possible solutions (for example: Pain, Cold intolerance, Underventilation, Joint deformities, Foot swelling, Swallowing difficulties, Scoliosis, Osteoporosis, Sleep apnoea, Incontinence, Coughing). Entries on Communication, Relationships, Sexuality and Support groups cover interpersonal issues. The last includes suggestions on how to lead a support group effectively. Lifestyle modifications have been proved to be one of the most effective ways of reducing post-polio symptoms. This area is well covered by topics such as Lifestyle changes, Pacing, Conservation of energy and Employment. Psychological issues are explored in the entries titled Coping, Loss, Stress, Positive attitudes, Depression and Spirituality. There are useful sections on Post-Polio Syndrome and its various symptoms.
The entries on Diagnosis of post-polio syndrome, Anaesthesia, Hospitalisation and Trauma would be very useful to photocopy for presentation to health practitioners who need to know more about the late effects of polio. The section on Trauma refers to traumatic injuries such as fractures and severe sprains, which need significant periods of immobilisation or bed rest. Polio survivors are particularly vulnerable to post-injury weakening at such times. "It has been estimated from clinical observations that [polios'] recuperation period after surgery, severe illness, or injury is at least three to four times longer" than normal. The period of immobilisation should be minimised but "a longer and more carefully prescribed period of rehabilitation and/or recuperation after traumatic injury can be very helpful for, and is often crucial for, a post-polio survivor to make a full recovery to the pre-injury level of function." There are also entries on Counselling, Diet, Fibromyalgia, Gastrointestinal tract dysfunction, Seating, Swimming, Wellness, Weight, Polio vaccines, Smoking, Independent living, Frog breathing and many more.

The book contains a short history of polio by Tony Gould, the author of A Summer Plague: Polio and its Survivors (published in 1996 by Yale University Press). He comments that polio is a unique disease "in the sense that ... in the words of the medical writer John Rowan Wilson ... 'its rise and fall took place within a single lifetime.'" Salk and Sabin, who developed the polio vaccines in the 1950s, did not receive a Nobel Prize. In 1948 Dr John Enders of Harvard had discovered a way to cultivate poliovirus in non-nervous tissue. This advance was used by Salk and enabled the development of a vaccine. Enders and his two colleagues received a Nobel Prize.

As the handbook is for physicians as well as polio survivors the entries sometimes contain technical details. Some authors have been more successful than others in explaining issues for lay readers. I find it more helpful to read about a psychological issue that affects me, if the writer adopts a discursive, empathic style of writing. This is difficult to do when writing a handbook entry. Thus while the entry on Loss has much useful information it is not what I would turn to for help on a day I was feeling overwhelmed by post-polio losses. A few items are only relevant to the USA, for example, the Americans with Disability Act and Disability Social Security.

The shortest entry, and the one that I found most intriguing, is titled Virus, Recurrence. It reads: "Attributing post-polio syndrome to persistent poliovirus or to a reactivation of poliovirus has generally been rejected, based on available antibody studies. The significance of poliovirus RNA fragments found in survivors with post-polio syndrome is unknown. Research continues in this area because the possibility and the consequences of a persistent infection caused by an enterovirus involving the central nervous system is of considerable interest." So it's wrong to dismiss the condition we dinosaurs have as being of no relevance to medicine just because we're a dying breed! Perhaps we are a valuable resource for medical research that should be treasured before it becomes extinct.


You may purchase the revised edition of "Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors" by writing to GINI at 4207 Lindell Blvd., #110, St Louis, MO 63108-2915, USA. The book costs $US19.50 (about $A30), which includes postage, and you can pay by bank draft or charge it to your credit card (VISA or MasterCard). Your order should include the type of card, the name of the cardholder, the card number, its expiry date and the cardholder's signature. The Network is currently negotiating with GINI to buy copies in bulk for sale to members and hopefully reduce the price. As this issue goes to press these negotiations have not been finalised. Further information will be given at the Annual General Meeting and in the December Newsletter.
Support Group Report

Bernie O'Grady
Support Group Co-ordinator

We are coming to the end of another successful year for the Network and its Support Groups.

There are 23 Support Groups based throughout NSW and the ACT. Many Groups come together for regular meetings, while others make telephone contact.

I would like to receive a written Support Group Report from all Conveners by year's end on the happenings and activities of your Group. Thank you to the Conveners who have sent regular reports throughout the year.

For many months now I have been writing that we still require Conveners for the Eastern Suburbs and St George / Sutherland areas of metropolitan Sydney. There are members in these areas who have been waiting for quite some time for a Convener to come forward so their Groups can get underway. If you live in these areas, and especially if you wish to belong to a local Group, please give some thought to whether you could help to get the Groups underway. Being a Convener is not a huge task, and the duties of the role can be shared amongst members of the Group. If you think you could help, why not give me a ring and talk it over. A comprehensive Convener's Information Kit is sent out to anyone interested in running a Group, so you don't need to re-invent the wheel.

While on the topic, a Convener is still needed for the Northern Inland Support Group ably convened for many years by Barbara Chapman-Woods of Tamworth. Barbara recently had to resign as Convener of the Group to return to Sydney. It would be a shame if this long-running Group closed.

Also, Cliff Cook will be standing down as Convener of the Lower South Coast Support Group at Tathra after their end-of-year Group barbeque. Cliff has advised his Group of his decision, and is anxious for someone to come forward to be Convener. It is important that the Group members continue sharing, supporting and encouraging one another.

I'm hoping to hear from members in all four of these areas soon.

Transport Needed

In the STOP PRESS notice mailed in August, member Gwen Toohey from Saratoga on the NSW Central Coast advertised that she had an electric bed which she was willing to give away to a good home.

Maura Outterside from Earlwood, an inner suburb of Sydney, rang Gwen saying she would like to have the bed. Maura does not have transport to get the bed to Sydney, and is appealing for the goodness of a member or friend who could transport the bed for her. If anyone is able to assist, please contact Maura on (02) 9718 5803.

I hope to be able to catch up with as many Conveners and Group members as possible at the Annual General Meeting on 30 October. In the meantime, if anyone has any queries about the Network's Support Groups don't hesitate to give me a ring and have a chat.
You may recall that the Management Committee recently sought comments from members describing how valuable the Network's services are to them, in order to support our funding proposals. Over the last three months my mail-bag has overflowed with positive comments about the Network and the support it provides to members. This is extremely gratifying and more than a little humbling. With the kind permission of the members below, I would like to share their responses with you, and am sorry that space did not permit the inclusion of more excerpts. Thank you to all those members who took the time and trouble to write in.

The Network—essentially the care group who maintain the organisation and expand its support and services—and the knowledge of others in a similar situation to myself is an incalculable benefit to me. Without the Network's presence and energy I would feel isolated and deprived of up-to-date information. This work enables me to be positive and proactive professionally and personally—I doubt that I'd feel as confident without the support I'm given—or can tap into when I need it. (Jean Underwood, Empire Bay)

I am most grateful for all the work you do. Since becoming a member of PPN I have learnt much from the Newsletter and the publications you have offered. The scientific, medical and anecdotal descriptions of polio and its management, and the how and why of the decline in capacity of polio survivors in later years, provide information that is very useful in day to day living. I have learnt to understand my fatigue and not to push myself as I did before. I can stand up to people who expect too much of me. I can resist those members of the medical profession who try and foist medications and procedures on me which have been found harmful or dangerous to polio survivors by research reported in the Newsletter. I had hunches about many of these things before. To have the research evidence to back them is tremendously empowering. (Dr Shelley Phillips, Kirribilli)

The Post-Polio Network has completely changed my life. After years of being almost "normal", the gradual and eventually severe changes that were occurring in my body were mysterious and distressing. I was unaware of other polio survivors' experiences—in fact, until I met the Network I had only met one or two polios in my life. The benefits of the Network have been most valuable to me—in terms of education and management, mutual support and social benefits. The meetings, seminars, publications, newsletters, reprints of studies, and support group have been of such benefit to me personally that I can only speak of the Network in superlatives. (Ivy Smartt, Drummoyne)

I now have a much better understanding of my medical situation and what I must expect from the late effects of polio. I have passed information from Newsletters to my doctors who have both been interested. In particular, the information has been most valuable in determining quantities of medication for me. Belonging to the Network has literally changed my life and made my outlook more positive. (Norma Hinde, Mosman)

Membership of the Network has given me a new outlook on life over the past 10 years. It alerted and explained to me what was happening to my body. It has kept me up to date with research and findings. Being a Convenor of a Support Group has allowed me to develop a network of new friends and draw strength and assistance from their support. Attendance at Seminars and Conferences has widened my involvement in the Network and provided me with new goals in my life. The Network, its services and the people in it have given me support, friendship, challenges and rewards and has provided a vital interest in my life. (Neil von Schill, Lavington)