POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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Editor's Corner

First things first - the Network's Annual General Meeting will be held on **7 May** at our usual venue, Paraquad at Homebush. The Committee for 1994/95 is elected at this meeting. You as members have the opportunity to give feedback to the outgoing Committee about the past year's activities, and to have your say about what you would like to see the incoming Committee undertake over the coming year.

As we approach our fifth birthday, it's timely to consider what the Network has achieved for its members. In a nutshell, we have dramatically raised the level of awareness of polio, and its late effects, in the community. After five years the Network is a strong and growing organisation with new membership applications being received every day. Today we are also widely acknowledged as the peak organisation in NSW for people who have had polio and are therefore consulted on issues of importance to you. This has all been achieved through the hard work of twelve dedicated people each year. Some of them keep coming back for more, because they appreciate there's still a long way to go. This year we hope YOU will join the Committee. We are pretty good at dividing up the jobs now, and everyone always pitches in to help, but we need the people in the first place, especially since some Committee members who have been with the Network from the beginning are not restanding for election this year. This is your opportunity to help keep your Network a vital organisation which meets the needs of its members; you will be richly rewarded as you assist the Network to continue to reach out to people who are experiencing the late effects of polio. I'll get off my soap box now - see you at the AGM! Members' copies of the Annual Report and Financial Statement will be available at the meeting, as will the Winter edition of the Information Bulletin.

At the Seminar following the AGM we will be exploring the talents of four of our members - see page 2 for full details of both the AGM and the Seminar to follow.

The Committee would like to remind all our members that membership fees ($10 employed, $5 not employed) are due from 1 April 1994 and should be sent to PO Box 888, Kensington 2033. A renewal form is enclosed for your convenience. We also thought it was time to have a party, and what better excuse than our fifth birthday! So that we can gauge your interest in having a big get-together (and to help us to work out what form it should take), there's an Expression of Interest slip at the bottom of the renewal form for you to complete and return with your renewal. Once we've collated all the responses we'll be able to finalise the date, venue and cost and advise members.

Now to what's in this Newsletter - you'll find the quarterly Support Group update on page 3, the Question and Answer session from the talk given on 20 November 1993 by Dr Jill Middleton (Rehabilitation Specialist, Prince Henry Hospital Post-Polio Clinic) on pages 3-13, and items of interest in Bits 'n' Pieces on pages 14-15. Brief details of a couple of exciting articles to be included in upcoming issues of the Newsletter are given on page 15. Finally, there are two letters from my mailbag in Post-Polio Post on pages 15-16. Happy reading!

Post-Polio Network (NSW) Inc : Annual General Meeting

Date	:	Saturday, 7 May 1994
Time	:	11:00 a.m.
Place	:	Paraquad Auditorium, 33-35 Burlington Road, Homebush (between Rochester and Meredith Streets This venue is wheelchair accessible, with off-street parking for approximately 40 cars. Entry to the Auditorium is only a short distance from the flat car-parking area.
Business	:	Confirmation of previous Annual General Meeting Minutes Presentation and adoption of Annual Report, Financial Statement and Auditor's Report Election of Management Committee Election of Auditor General Business
RSVP	:	Phone Rae on (02) 337 6315 by Thursday 5 May 1994

Seminar : Members' Talents

Please bring along your own lunch (tea and coffee will be provided) to have at the conclusion of the AGM. Before the Seminar proper commences, David Happ of Walkabout Electric Vehicles, will briefly demonstrate the Walkabout Scooter and the Reclina-Lift Chair. The Seminar will then follow, with some of our members talking about, and demonstrating, what they are achieving.

Margaret Greig is a well-known artist who paints with the brush held in her mouth. Margaret will demonstrate her art and is looking forward to sharing her knowledge with the audience.

Suzanne Rangi is a current Committee member, convener of the Roselanders Support Group, and budding poet/author. Suzanne will recite one of her poems.

Rosemary Shepherd is a lace specialist who works in the Education and Visitors Services Department at the Powerhouse Museum. Rosemary will discuss the art of bobbin lace-making and give a demonstration. Copies of her book on this subject will be available.

Alan Quirk will be well known to many of you as a long-time member and supporter of the Network. Alan will give a talk about how his trained dog, Zuga, helps him out in various ways. Zuga will no doubt have his say as well.

While discussing the structure of this Seminar, the Committee considered the possibility of having tables available for members to display the results of their hobbies. For example, a country member who is unable to join us on the day has already sent down an example of her work - I've reproduced her letter on page ?. So that we can properly cater for anyone who is interested in attending the Seminar and displaying items, could you please ring Nola on (02) 636 6515 by Friday 29 April to organise the details.

Upcoming Seminar : 6 August 1994

Don't forget that Elizabeth Hastings, Disability Discrimination Commissioner, will be speaking at our August Seminar. The venue is yet to be confirmed - watch this space.

SUPPORT GROUPS REPORT

Hi to you all, especially Support Group Convenors and members. Thanks to the convenors who send in their group reports. These are required by the 22nd of MARCH, JUNE, SEPTEMBER, DECEMBER, for inclusion in the next Newsletter.

The two new groups of BASS HILL and CAMPBELLTOWN have already met. Convenors, Andreana (727-7502) and Brian (618-2279) would love to hear from anyone interested in joining. Most of the new members did't know anyone else in the area who had had polio and many were interested in discussing the various problems and health effects on themselves and other people.

Some news from other groups -

ACT: Convenors were arranging guest speakers for several of their'94 meetings, including Dr. Jill Middleton (9th April) and a speaker on the ACT Taxi Subsidy Scheme for the Disabled and the Mobility Allowance (4th June).

COFFS HARBOUR: The first meeting was attended by 23 people who were happy to see each other after the break. The venue for the March get together was the local Botanical Gardens.

Please Note - Convenors are :
Anne O'Halloran, 20 Crescent St.East, Urunga, 2455 - Ph: 066 55 5204
Nancy Bonhan, 51 Gallipoli Rd. Coffs Harbour, 2450 - Ph: 066 52 5083

GRAFTON: Meetings are now held at the Grafton Regional Gallery which has excellent accessible facilities and members are able to admire the art works at the same time! For a later '93 meeting the guest speaker was a water/therapy aerobics instructor who specializes in rehabilitation at South Grafton Indoor Pool. Next meeting is 18th April, 1994.

HUNTER: At a recent meeting members enjoyed a demonstration and talk (by Barbara Merrington and friends Dawn and John) on diet and nutrition products from "Reliv". They are also planning a bus trip to the Independant Living Centre at Ryde, which members should find helpful.

INNER WEST: Several members attended the Network's March Seminar and learned a lot from Monika's talk and slides - as I'm sure we all did. The group shared an enjoyable and relaxed meeting on the 12th March.

I'm delighted to report that we now have a convenor for an UPPER NORTH SHORE support group:

Barry Palmer, 7 Beryl Ave. Mt. Colah, 2079 - Ph: 457-9950 (A.H.)

Thanks to you all and best wishes for your 1994 meetings.

Shirley Roach Support Group Coordinator (02) 759-1578

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"THE POST-POLIO CLINIC - QUESTION & ANSWER SESSION"
(as promised in last Newsletter)

Q. How do you determine who has had polio and who hasn't?

A. People who have not had any obvious muscle involvement and who don't have any clear evidence of paralysis, it may not be possible unless you do a lot of high-powered immunological studies to say whether the person has had poliomyelitis as an illness. If you have paralysis and weakness and reflexes in a patchy distribution, i.e., assymetrical, and have had an index illness which is consistent with it, then it is highly probable that a person has had polio, although not,

in fact, conclusive, because there are some viruses which will do the same thing, but much less commonly. It is generally uncommon for it to be a purely muscle weakness without changes to the way the feeling nerves work. There is a group of people who almost certainly did have poliomyelitis, did have significant weakness, but made a good recovery and in the course of their recovery regained strength in all their muscle groups to an extent where, on our clinical testing where we measure muscle strength, the muscle strength in those groups is what we would call "normal". The normal range for the population of muscle strength is enormous. It is from very, very weak little weaklings, but can be quite normal, to weight-lifters. So there is a lot of people who may not be anywhere as strong as they should be but still fit in the "normal" range. In some of those situations you can actually show, during electrical tests on the muscles, signs that are strongly suggestive that the person has had a polio-type illness, and that person must be prepared to have needles stuck into them which can be most uncomfortable. If immunological studies, looking at antibodies, are done and shows evidence of the person having been exposed to the virus, it still doesn't say that their nerves and muscles were affected, as so many people had that exposure and their nerves were not affected. So if a person wants to try and find out, the best thing is to see a neurologist who does electrophysiological studies, that's on the basis of seeing if there is any hard evidence but, whether there is or not, I don't see that as excluding the problem or excluding the diagnosis absolutely.

Q. Why do all doctors, in the case of foot drop, want to fuse the ankle joint?

A. As one doctor I don't want to automatically fuse the ankle joint in people who have foot drop. Fusing the ankle is a way of dealing with the problem of foot drop which largely is that it interferes with the way you walk, particularly with the toes getting in the way, so that you trip, particularly ascending stairs or slopes. If you have young children developing their mobility skills, and children going through the teen years where they don't want to wear their calipers or orthotic devices, then there are certainly advantages to fusing the joint and stopping the problem of the foot flopping, so that they can then run around without tripping and without having to wear an orthotic device, a caliper or splint. Without fusion, they would have a lot of falls when not wearing orthotic devices, or would place a lot of extra load on other joints which can lead to damaging these, particularly when the joints are developing, and lead to all sorts of extra problems. That is the reason why joint fusions have been used a lot to stabilise, and to eliminate the person having to wear orthotics or to enable the person to get away with wearing much smaller or less complex ones, than they might have needed if they have a lot of unstable joints.

Q. How do you measure and record muscle strength?

A. There are quite a few different scales that are used in measuring muscle strength in a clinical situation. Because they involve a person subjectively feeling the strength, they have limits in how well you can reproduce them either in different people doing it or even in the same person doing it at different times. I personally use a five-point with a zero scale and there are various different scales used. I haven't come across a ten-scale, but I am not good enough to be able to give ten levels. If you want a very accurate measurement of muscle strength, you have to use other equipment to actually measure the force and the force vectors. This can be done, but it takes a lot longer and you must have the equipment, and measuring the strength of muscles across some joints can be quite difficult to do because of the way you have to try to isolate them to then tie into the equipment can, in practical terms, be quite difficult, so we tend to use scales

that are fairly simple reproducable like, "no movement ata ll", "flicker", "weak movement but not anti-gravity" and so on, up to the final top of whatever scale you use to be what we would perceive as being "normal", with the proviso that "normal" is a very big category and therefore what comes into "normal" for that assessment may not be full normal power for that person.

I chart out the basic muscle groups - mainly upper limbs and lower limbs - as part of my assessment in terms of practical issues as to how a person is likely to have problems with walking and those sorts of activities and partly so that I have a record to compare with in two years time when I again see the person. This enables me to say either you have dropped three or four major categories in strength compared with my record and you are feeling much weaker, but you feel your increased weakness has become worse, or with another person in a couple of categories you have gone up or or two and you are telling me you are not doing as well. Not that it is wrong, but that it is interesting. I think with any of these things I see where we are up to, really is getting information - we really can't say this proves that or whatever.

Q. There are some places, particularly in Victoria, who have a machine which measures the muscles fairly well. Is there one in Sydney?

A. I'm not exactly sure which machine you mean. There are various machines which do them. The ones which you can adapt to use on a lot of muscle groups tend to be fairly expensive, like the Sivex machine, which must be tied to a computer to actually give a recording and you have to scale it and then set up ways that you can line joints to take out gravity effects, etc. They are certainly around, in fact, when we did the post-polio study we tried to use a Sivex with one of my colleagues but the idea never quite got off the ground, in terms of actually getting anything out of it for results, and that was just for a single joint. You are probably looking at quite a prolonged assessment. We don't have one that is actually functioning at Prince Henry so we are not in a position to do that there. If anybody had the set-up and had enough people who were interested and who were going along, and if anybody came to my clinic who had had it done, I would be interested to see the results. In many ways, it obviously would be much better if one could do that to obtain a much more objective assessment and a record of an objective assessment for us to then follow through. When Professor Gandevia does his measurements he does in fact measure the power of the pull with a measuring instrument which is calibrated, not just with my subjective estimate.

Q. Can you comment on reports of people having a dietary supplement with 'L-Caratene' and subjectively feeling stronger?

A. In terms of post-polio I cannot comment.

Q. What is the growth factor?

A. There is a factor called 'Somatomedin-C' which is an insulin-like growth hormone that is reported to be low in some people who have post-polio symptoms and we are actually measuring that in people who come to the clinic and we are coming up with some people who are a touch low and as yet I don't know what we should be doing about it. We are looking, first of all, to get enough numbers of people to also look at our muscle testing studies and look at all the other factors and then that would obviously be one area we would look to be thinking about maybe trialling something. I am, personally, very cautious about trialling any pharmacological agents when we don't really know what the problem is to start off with, because I am always worried that it is so easy to rush in on a good idea and not realise all the holes you can fall into. Many of the people with these problems are finding that their lives are significantly altered by the problems already. If I add any-

thing, then that could be catastrophic to them, even if it is only a one percent or five percent drop from side effects. I mention that particularly because there are some medications which we throw around for other things which do seem in some people to make their symptoms worse, and some of the cardio-vascular medications certainly fall into that group. That, of course, doesn't mean that anybody who is having their hypertension treated or anything like that, should immediately throw away their tablets. If you are on a lot of medication, I think it is always a good idea to talk it over with the doctors who are prescribing them, what they are all about and making sure that you do really need to be on them.

Q. What is the waiting period for an appointment at the Clinic?

A. At present Dr. Middleton can only give one afternoon a week because of other work and the hospital itself only has the facilities for one clinic per week. It takes approximately 1-hour to 1½-hours to see a new patient. At the moment Dr. Middleton sees two new patients and two follow-up patients a week, and finishes her clinic at 7-8 o'clock in the evening, by the time she dictates letters, etc. The person who has the last appointment is often unable to have blood tests, X-rays, etc., as these services cease about 5.00 pm. These are some of the types of problems with which Dr. Middleton is faced. At the moment the hospital doesn't have the resources to have any more doctors The situation is not ideal, but Dr. Middleton would rather see a client for 1½-hours and again for ½-hour that see them 10 times for 10 or 15 minutes and never really have the time to actually sit down with them to feel that she has gone through with them most of the things that they want to talk about or that she needs to look at in the first instance. The situation at Prince Henry may change next year because Royal South Sydney Hospital is closing and is being moved to Prince Henry and it is possible that a doctor from there may look at also running a clinic. If that happens, those on the waiting list will be contacted and offered an earlier appointment.

Q. Has the 'restless leg syndrome' been found in many of the people seen at the Clinic?

A. No. I have only had two or three people with a reasonably strong suggestion of restless legs and with that number one cannot draw any reasonable conclusions about it at all.

Q. How could there be more clinics made available or more time in the Clinics?

A. In terms of the logistics of the Public Health Service I would have to say, I don't know. I am not in the management area. I work at Prince Henry - I am a half-time staff specialist there and I work in the spina unit and in the general rehab. so I have commitments all the way through. I would personally find it very difficult to say I am not going to be involved anymore in the spinal unit because I want to double what I amy doing with the post-polio people. We have a couple of other clinics we want to set up for other disability groups which at the moment we cannot do either. There are all sorts of political and socialogical issues related to why services are provided.

Q. How many visits does it take for a first-up assessment?

A. On a first visit I would go through what the person's problems are, the history and other problems and then chart out their muscles - do a sort of brief examination, depending on what else may be evident as problems Then I check thyroid function, check for anaemia, check for normal liver and kidney functions, which are basically ways of screening that some of the more common other things that can cause these symptoms are not involved, if they are, picking them up, because many of them can, in fact, be treated very effectively. Now in that situation, if the person

has had a lot of these tests done through their G.P. or other specialists, then I might try to get hold of those results by contacting the other docotrs or if they can bring the results, then the tests need not be repeated. Usually there are a few things I like to look at as tests. Often I like to to look at Prof. Gandevia's muscle testing studies because I have found them quite helpful when considering advice to people. So that would generally involve lining these things up and then coming back to see me usually once in the clinic again. After that it really depends on what the problems are, what I can suggest (if anything) and what particular use there might be in coming back afterwards rather than just going back through your G.P. for medium term follow-up. So it is variable and individual. But for most people it would be one and a follow-up to the clinic with not infrequently other tests or other assessments or other consultations with other of my specialist colleagues and not all necessarily at Prince Henry. For example, quite a large number of people who tell me they have problems with their breathing, sleep apnoea type of problems or symptoms that may be indicative of that and as there is not a sleep apnoea study unit at Prince Henry or Prince of Wales, I would refer those people to colleagues at Prince Alfred.

Q. How can you obtain equipment to support your breathing when you run into breathing problems from muscle weakness?

A. The first thing is to clearly diagnose what exactly is occurring, in terms of the respiratory system. You can run into problems with breathing at every level from the tiny little air cells in the lungs (probably not related to polio at all but from asthma-type things, chronic bronchitis) all the way through to weakness of the diaphragm, weakness of the intercostal muscles, and up to problems with air-way obstruction, particularly at night with the obstructive sleep apnoea-type problems. They will all tend to make you feel breathless and fatigued, etc. Some you can distinguish from the symptoms but mostly you really need to get the problem sorted out properly, which means going to a specialist respiratory unit, preferably one that can do or has access to a sleep-study type unit that can really investigate your breathing and control of breathing as well as lung function. There are all sorts of equipment but it is essential to find out exactly what the problem is. For example, use of oxygen equipment. Having supplemental oxygen can be quite toxic and it can stop you breathing if you have certain types of respiratory problems. With some problems you might just need a portable ventilator and with other problems a person may need just to learn how to pace their physical activities. Other problems may need ventilator support, other problems may need portable oxygen, or whatever. So it is absolutely essential to find out exactly what the problem is and that means usually going to a specialised respiratory unit. Most of the big hospitals would have some degree of specialised respiratory unit. I usually deal with Prince Alfred and as they have a fairly high-powered sleep studies unit which has been useful, I tend to send most people whom I think have a problem there for a general assessment. But the more general respiratory assessments do not have to be through a sleep unit but a specialised respiratory unit.

Q. Do you have any thoughts or advice on stress management for people who have had polio and those with the late effects of polio?

A. I think stress management is very important in a whole lot of areas in our lives. We are all subject to stress, with or without added problems. People who have had polio and who have been left with significant weakness or paralysis, in my experience, seem to have become a particularly high-achiever group and particularly driven and, I think, as a result, they are particularly subject to increased exposure to potential problems with stress when or if they start to run into prolems functioning physically at the level they used to function. In

that situation I think looking at stress management techniques, relaxation techniques, things like that, can be very useful, if the person is prepared to look at them. I usually suggest that the person see, preferably a clinical psychologist, who is experienced in relaxation techniques, stress managment, those sort of approaches particularly in a rehabilitation context to get some advice and look at techniques to use for stress management as an individual. I don't think management of stress is going to cure the post-polio syndrome because I don't think it is caused by stress, as such, but I think that people who tend to be subject to a fair amount of stress because of the type of life they tend to be living who then start not being able to function physically as well as they used to are subject to a much increased load of stress, which may benefit from them learning how to manage it better. I don't believe in pills and potions for that because: a) I don't think they work; b) I think they can be harmful, particularly as they increase muscle weakness and d) in principle, I don't think that is the way to go anyway.

Q. As there is no treatment proven as yet for an hypothesized basis of post-polio syndrome, namely, loss of function of the motor units that have been functioning, and in that context would you consider acupuncture to be useful?

A. The short answer, in terms of acupuncture is, acupuncture is very useful for quite a lot of musculo-skeletal problems. I would see it to be quite useful to some people, particularly for pain-related problems. I, personally, cannot see in a scientific basis on what is known yet how it could help the muscle weakness directly, but that is not to say that I wouldn't see that maybe some knowledge could come to hand which would show that it could. It is just that I can't see how it would, on current knowledge. I certainly think it is clearly useful for a lot of conditions of discomfort and pain and discomfort can certainly make muscles function a lot less effectively. So in a back to front way, I can see ways where it could work. However, acupuncture practised by responsible proponents of the art is not usually attended with much in the way of side-effects and I would certainly be interested to see any studies on its efficacy in practice and then try and sort out how it works, as and when it does and I think certainly it is always useful to try as a therapeutic approach for musculo-skeletal pain disorders and for a lot of related things like that.

Q. What does Professor Gandevia's 'Muscle Testing Study Programme'do?

A. Prof. Gandevia's muscle testing study basically looks at using one muscle group across the elbow joint (the elbow joint flexors which are the ones that bend your elbow) and what he looks at is, initially, the power of the muscles in the individual which he measures and records and that is the power to start off with when he asks the person to contract that muscle the maximum amount they can. He will than stimulate that muscle with an electrical current to make it contract. The current is delivered through the skin with surface electrodes (you don't have a needle inserted). The muscle is then stimulated electrically with an stimulas which is increased until the muscle reaches a maximum contraction and then as you increase the stimulas beyond that it doesn' contract anymore strongly and so that is said to be the maximum contraction it can give. He then looks at how well the person can then voluntarily when they say "I want to make my elbow bend", how strong that contraction is compared to the best contraction they can get from the electrical stimulus. Normally, it is 90 percent plus. So between 95 percent and 100 percent of the maxiumum stimulus in a normal situation.

The second part of the study basically looks how that muscle performs if you keep exercising it. So what he asks one to do, is that you contract the muscle but you contract it not to the maximum you can get but

to maybe 40, 50, 60 percent and he has a standard amount, and the way you judge that is because he has the machine and, having measured what your maximum is, say that is 40 newton metres then on the screen he can bring a marker down to say, 30 newton metres and there is a line there and you contract then to pull the line up to that marker so you know you are pulling to three quarters so that you can actually determine to what percentage of the maximum you are contracting. You then just keep repeating that for three quarters of an hour, but you have little interruptions, which are to again try to make it contract as strongly as it possibly can and then agin to make it contract as strongly as you can make it contract with the electrical stimulus, so that you can look at how its best contraction changes over time and with that regular exercise the maximum strength you get will go down, over time, so that by the time you reach three quarters of an hour you feel tired and the muscle feels tired and it doesn't pull as well.
There is a normal pattern to the way that happens so that happens in every normal muscle. It can also be abnormal in a number of ways and the ways we have found in some people with these post-polio symptoms are basically twofold; one is that the person can't get that 95 to 100 percent contraction when they voluntarily try as hard as they can (and some people are only pulling 70 percent) of what you can get out of the muscle with an electrical stimulus and the other way that it can be abnormal that is of significance in this context, is that it can fatigue more quickly, so that instead of going down, for example, from 100 percent of what it was at its first contraction to say, 60 percent after three quarters of an hour, it might go down to 20 percent
There are many more abnormalities that you can have with the test and many of them may resolve in the test not telling us anything one way or another. The biggest problem I found was that some people get pain and if they get pain then we can't tell whether they are not contracting the muscle because of the pain or because of something else and anyway we usually don't persist, unless it is just minor discomfort. That is basically what we do and don't find out from the test.

Q. As people reduce their amount of physical activity they tend to put on weight. Is there a solution to that?

A. Yes. You just have to match what you eat in terms of calories to what you can physically use. The problem of exercise itself is a fairly difficult problem and you are caught between the two extremes. There is no doubt that if you don't exercise muscles they will get weaker and they will disappear and the only way to overcome that is to exercise them. The other end of the spectrum is that if you over-exercise muscles and over-use them they will also get weaker. What you have to do is try and find the peak of the curve where you are exercising them to an amount that is maintaining a good degree of strength for that muscle. Now the problem that I find that many people who have had poli run into in that regard is that where they have muscles that have been significantly weakened but they need to walk with or do things with their arms they have been using those muscles at an abnormally high percentage of their maximum capacity. Normally, when we are walking around and living our lives, we don't use muscles at their peak, we very rarely make them really work hard and mostly they bumble along at maybe 10, 30, 40 percent of what their capacity is with lots of rest in between. However, if that amount of bumbling along in a normal person gives you X-amount of muscle strength and if you then have had polio and if you end up with muscles that have only 40 percent of normal muscle strength, and you insist on still physically wandering around and doing things as the same amount as the normal person in the normal population who hasn't that paralysis, then in fact you are probably working your muscles at 80, 90, 100 percent of their maximum capacity and they certainly run into over-use problems, physiologically in terms of the way that all muscle cells and molecules work. So I

think you then have to look at what you are doing physically in terms of activities and you really have to bring your conscious brain to bear to decide how you are doing exercise and what is appropriate for you and you really have to try and get out of the pattern of judging what everyone else does and what's normal for your age or normal for any other of those scales. It has to be what is suitable for your muscles. The muscles in one arm may be quite different from the muscles in the other arm. With your diet it's the same thing. You have to tailor your diet in terms of calories to what you reasonably use up in muscle power. Now you do need energy from your diet for a whole lot of things like kidney function, heart function, brain function, those sorts of things, but in terms of the actual bulk of the calories you put in, that really is for bulk muscle work. I don't know of any shortcut for that. It is also very important, if you are running into a situation where your muscles are not doing very much, that you watch your diet to ensure that you are getting a good balanced nutritional input of all the vitamins and minerals etc, and that really comes from varieties of foods and from good quality foods, and it means I guess that you've got to (even more so) avoid all the naughty things which have lots of calories that use up your calorie allowance, which means you then don't eat your meat and vegetables etc which give you the vitamins. Although you can get multi-vitamin pills etc (in some circumstances they may be useful when people are on a very restricted diet) there is no doubt that a varied, balanced diet, with lots of natural fruit, vegetables, proteins etc, gives you a much better balance of all those small important things like a whole range of the different vitamins, carotenes, which you can easily miss out on if you have short-cut diets, particularly with small amounts in diets.

Q. Are there any statistics on the life expectancy of people who have had polio?

A. No doubt there are, but I can't quote them for you. The only thing I would say is that, certainly, people who have had polio who have had problems with respiratory system involvement in the past, have died young because of respiratory problems which I think now we are in a much better position to treat, because of better technical support for breathing. I guess the other area where people with polio who survived the initial illness do seem to be particularly more prone, are things like early cardiovascular problems which I think probably relate directly to relative inactivity, lack of exercise etc, but that is only a very fuzzy sort of observation. I have personally treated several people who had polio sixty years ago in their twenties, and I have one patient who I remember seeing three or four years ago (not in a post-polio context) but who had had polio and who I saw because she had fractured her hip - and she was ninety-three.

Q. You said earlier that some of the pills and potions for muscle stress like tranquillisers, particularly, say, Valium, can cause muscle weakness. Can painkillers also do this?

A. Certainly some of them can. I would doubt that some of the simple ones like paracetamol would be likely to do much of that, but certainly if you get onto the stronger ones, particularly narcotics, they could well make muscle strength worse. I have a golden rule about pills and potions and that is that any medication can give any side effect to somebody, so there is no absolute reason why somebody couldn't perhaps become weaker, as far as I could see, from any of the medications. Remember the golden rule with side effects is that anything can do anything to somebody somewhere along the line - one just has to keep an open mind.

Q. When attending the Clinic, what sort of medical information should we bring along?

A. In fact any medical information you have but particularly if in recent months or the last year or so you have had any blood tests, bring the results of

those. Any assessments from other doctors/specialists you might have seen, any x-rays are always worthwhile bringing because if you have joints that are playing up somewhere along the line you would have had an x-ray; x-rays of the neck or back that may have been taken, even if quite a while ago, are certainly also of interest.

Q. Can you talk about improvements in mobility aids?

A. If you are looking at changing your mobility aids and that sort of thing, in general it is most effective if one does that in the context of a rehabilitation doctor, the patient and a physiotherapist (and an orthotist if you are involving splints or callipers) all meeting together. Sometimes you can say "this is the problem", you can do "this" and it will fix the problem and off you go, but that in my experience is uncommon. It is more often a complicated situation, and it's usually a question of "let's try this as it is likely it will help" - then we have to look at it again because maybe something else will happen and we might need to re-adjust and then maybe that will cause another problem. In that situation I think it is very difficult to try and do in detail from a clinic that you are not going to attend frequently which is one of the reasons why I like people to go back, particularly where there is a rehabilitation service, and find your rehabilitation specialist and physiotherapist and work together with them, because then you can look at your pattern of how you are walking and look at it in detail, play with different orthotics, try this, that, and the other, and hopefully iron out a whole lot of little problems and come to a resolve that at the end gives you the best result. I know there are problems with orthotics, of not being satisfied with orthotics. I personally find it very difficult to prescribe an orthotic if I am in a situation where I am not going to see it afterwards and preferably have the person working with a physiotherapist for a bit of time as well as with the orthotist and with me, but particularly the physio, the orthotist and the patient need to work together on how to get the combination to work best for that person, because there are so many different things that come into play and it often requires a fair bit of to-ing and fro-ing.

Q. Why has the clinic testing being based mainly on arms?

A. I think that is probably because Professor Gandevia's study is based on the arm muscles. In the actual clinic when I see people, I chart out arm and leg muscle strengths, right and left, and I have a look at the back (it's a bit harder to do muscle strengths there, but the significant thing is if you have a lot of scoliosis), and a few other bits and pieces. I listen to the chest and that sort of thing, and, of course, at least 50% of the assessment happens as the person walks in the door. In fact, I do chart out the legs as well as arms, test the reflexes etc. The reason the muscle study is done on the arm only is because it is a fairly simple arrangement that can be set up (it is fairly consistently reasonably reproducible) and you can repeat it and basically it is the same test. It is quite easy to stimulate the muscle and know you are stimulating the right one, not the wrong one. It is a fairly simple set-up, but if you then think of trying to set it up again to work a different muscle, you would have to rearrange all the equipment and we don't have the resources for that. Now we recognise that some people who have their legs particularly affected as far as they are aware, may not be having the affected muscle tested. Now there are a couple of aspects to the answer of that, one is that the polio virus, probably I believe, if it affected people's nerves, it affected them on a pretty wide-spread basis, although it was more apparent in some than in others, so that I think it is quite likely that muscles that don't look as if they were affected probably were affected a bit. Another aspect of it is that if that is not the case, then hopefully when we get sufficient numbers, we can break them down to the people whose legs were clearly affected and whose arms they felt weren't affected, and see if in fact as their own control whether that shows any different results. Yes, I would love us to be able to do those studies on every major muscle

group in every patient but those who have the studies done with Professor Gandevia know it takes almost half a day, and that is with just one muscle group. Logistically, we just couldn't go beyond that and so the decision was made to do it on that basis but we do recognise the potential drawbacks of that. At the moment, all we can do is to bear it in mind, particularly bearing in mind how we interpret things.

Q. What similarities are there between chronic fatigue syndrome and post-polio syndrome?

A. Abnormal fatiguability that is new or of recent origin is one of the cardinal symptoms of post-polio syndrome. I think chronic fatigue syndrome is almost certainly completely different from part of what we are seeing in post-polio syndrome problems. One of the reasons I say that is because people with the chronic fatigue syndrome have never shown any abnormalities on these muscle-testing studies. Professor Gandevia studied people with chronic fatigue syndrome with this very protocol before he studied the people with polio. My understanding is that the people with chronic fatigue didn't show any abnormality on this form of testing at all, even though they had quite subjectively very severe fatigue. I, therefore, think chronic fatigue syndrome is quite different from post-polio syndrome, but fatiguability is certainly a symptom of post-polio syndrome which itself is really a collection of symptoms, not a defined pathological entity which we can describe with any certainty as yet.

Q. Could you comment on immunisation, in particular there was apparently a report in the media that said parents had caught polio from changing nappies.

A. Poliomyelitis is a virus which comes from the gut and is excreted in the faeces, so certainly you could become infected with the virus through not being totally hygienic. If you catch the live virus certainly you may get paralysis on that one or two percent of the actual incidence of catching the virus which occurs. The first vaccine used (Salk) was not a live virus, but the second one (Sabin) is. There are three strains of the virus which you have to allow for because they are antigenically different. In other words, the body's immune system deals with them a little differently so that if you have exposure to one it doesn't automatically protect you against the other two, and therefore the oral Sabin vaccine (the live virus) covers all three strains. The live virus is a modified virus which is supposed not to cause paralysis. I guess if there was someone who was immuno-compromised there might be some sort of risk, but I would have to pass that (in terms of the exact details) to some of my colleagues who are experts in immunology and vaccinology and who would be able to answer that in more detail. Generally there is a very, very low risk.

Q. Do your patients go to neurologists or do you send them to see neurologists?

A. Yes and yes. Many have seen several neurologists, however some haven't seen any. Some I send to a neurologist for a more detailed assessment for a number of reasons, particularly as some have indications which suggest to me they may also have simple problems which may be treatable, such as carpel tunnel, which may be contributing to some of the problems people are experiencing.

Q. Is there any connection between scoliosis, polio and the carpel tunnel syndrome?

A. If you have paralysed back muscles then you often get a curvature in the spine which is basically what scoliosis is, and that will frequently become quite fixed, in other words it will become stiff and with that you can run into other problems, such as entrapment of nerves. Carpel tunnel syndrome is a bit different, in that it is a narrowing of a little canal that takes a

number of tendons and one of the big nerves to the hand across the wrist. For a whole range of reasons the space in the canal decreases and the nerve tends to be the first one to complain. That can be very readily fixed by opening up the tunnel. If you get a good surgeon who is used to carpel tunnel surgery there is usually no problem and it is usually quite effective. Any deformity which affects joints or limbs could alter the way the nerves grow and the way they are aligned. If the bones have not developed fully and they are a bit smaller, a tunnel could be smaller and one may be more likely anatomically to have the problem. However, in that situation there are not likely to be so many nerves because of loss from having had polio. I would expect that any increased risk of carpel tunnel would be that sort of structural relationship, but carpel tunnel problems are very common in the community whether or not one has had polio.

Q. There is recognised to be an increased incidence of carpel tunnel syndrome in people who have polio who use sticks and crutches. Can you comment on that?

A. In my understanding this also applies to a lot of people who don't have polio but use sticks and crutches because of other disabilities, so I wasn't looking at that as a predisposition due to polio as such but more as the mechanical predisposition and, certainly, if you are relying on strong stable wrists to walk on, then you need to be very careful about what you have done to them surgically. Anything which disrupts those ligamentous mechanisms may run into problems if you then try and wade through them (which is basically what the person is doing in that sort of situation. I think probably in that context if the person has severe carpel tunnel syndrome they may or may not need surgery, but they are going to have to look at different ways of getting around not using sticks and not, in effect, walking on their hands, unfortunately. I agree surgery is not necessarily going to give them the capacity to continue walking on their hands.

Q. Should adults who haven't previously been immunised against polio be immunised?

A. I think anyone who hasn't been immunised against polio should be, because adults can also contract polio.

Q. Have you been able to obtain people's past medical records, and have you been able to determine whether the treatment given seemed to be helpful?

A. There have been a few people who have some details of past medical records from childhood or from 20, 30 or 40 years ago. It has been very fragmentary, not really enough to contribute very much in concrete terms.

Q. Is it correct that every ten years a person should be immunised?

A. There are numerous diseases against which a person can be immunised. One which we need to keep our immunity against is tetanus. If the initial three-course dosage of immunisation against tetanus has been received, a booster injection every ten years is necessary to keep up immunity. Different types of diseases against which one is immunised have different life spans, and the immunity of individuals van vary, but tetanus is one disease against which I strongly recommend that people have current immunity.

That's the end of Dr Jill Middleton's Question and Answer session. Remember that although Dr Middleton is fully booked for 1994, the Post-Polio Clinic now has a second rehabilitation specialist, Dr P. Katrak. To make an appointment to see Dr Katrak phone (02) 694 5931 and have your Medicare number handy. A referral from your doctor is also necessary.

Bits 'n' Pieces

- Joan Clarke, whose article "Treating Post-Polio with Acupuncture - Worth Trying?" was published last issue, has asked me to make a minor amendment to one sentence in her paper in order to make her meaning clearer. The sentence (which began at the bottom of page 10 in issue 19) now reads: "The first reported on the results obtained in 792 cases treated by using both western and traditional Chinese medicine, claiming an improvement in about 90% of patients, including 44 cures."

- The Post-Polio Support Society N.Z. (Inc.) has written with details of the National Conference they are holding on the 23rd, 24th, and 25th September 1994. They advise the conference has attracted international speakers and will offer a unique and varied program. To quote from Publicity Officer Dianne Tippins' letter:

  "Venue is the Auckland Airport Travelodge in Mangere and is only minutes from Auckland International Airport. This first class facility offers good ground level accommodation, conference rooms, and restaurants all with easy access internally and externally. Very well suited for the special needs traveller.

  For those of you who would like to attend the conference and then spend some time touring ... September in New Zealand is springtime and weather wise is generally a mild climate with cooler evenings. Also at this time of year we can expect occasional spring showers.

  We are presently fundraising for the conference and as yet have not set any registration fees, but plans are to keep charges to the minimum. You will be interested to note that generally the US dollar is worth twice that of the NZ dollar.

  To help us with travel discounts could you please contact us if you have any members interested in attending as we are working with the airlines on discount travel to New Zealand.

  Please contact me or our conference secretary, Mr Ramon Chandler, if you or others are interested in attending (we would like some indication of numbers as soon as possible) or if you want further information on either the conference itself or travel details etc."

  If you are interested in attending could you please forward an **Expression of Interest** to Mr Ramon Chandler, PO Box 51-641, Pakuranga, Auckland, New Zealand as soon as possible. You need to advise the following details to Ramon:

  - **your name, address, telephone number, and the number of people attending**
  - **whether you are a polio survivor, medical person, or other interested party**
  - **whether you will be staying at the Auckland Airport Travelodge**
  - **whether you will be travelling by air**
  - **whether you require more information on the Conference**

- Network member Associate Professor Mary Westbrook (Department of Behavioural Sciences, Faculty of Health Sciences, The University of Sydney) has been invited to present two papers and participate in workshops at the Sixth International Post-Polio and Independent Living Conference which will convene from 16 to 19 June 1994 in St

Louis, Missouri. Mary will be bringing back a wealth of information and knowledge from this Conference, and as usual Network members will benefit since Mary has once agreed to speak at one of our seminars. More news on this later in the year.

Finally, don't forget the Disabled Peoples International World Assembly to be held at Darling Harbour Convention Centre from 5 to 9 December 1994. The Network is assisting with some logistic arrangements for the World Assembly. In addition, the Network is hoping to be involved with the Pre-Assembly Program being held on 3 and 4 December, possibly through the presentation of a paper at a workshop, since this will provide a unique opportunity to address both local and international Assembly delegates. We'll be getting more information out to you soon on these matters.

Upcoming Issues

- Amanda Piper from the Sleep Laboratory at Royal Prince Alfred Hospital has sent in a very detailed article about sleep apnoea and how it may overlap with the post-polio syndrome. Unfortunately, space did not permit its inclusion this issue, so watch out for it next time.

- As many members who volunteered as "guinea pigs" will be aware, Professor Simon Gandevia (Department of Clinical Neurophysiology, Prince of Wales Medical Research Unit) and Professor Ian Neering (School of Physiology and Pharmacology, University of New South Wales) have been conducting research into the late effects of polio. They will shortly be attending a conference in Bethesda, USA, at which will be leading health professionals in the post-polio field. Professor Neering has offered to contribute a report on the conference for inclusion in the Newsletter. We hope his report will be ready for the next issue.

Post-Polio Post

- I was surprised and delighted to receive a parcel and letter from Mrs Yvonne Stone of Kindee:

  "As I can't attend your meeting in May I have decided to share my hobby too. Perhaps you could raffle or auction this little knee rug - very cosy for old polio knees - or give it away. I spin the wool and dye it with natural dyes, mostly gum or wattle leaves or the green is wild tobacco.

  When we lived on the Central Coast all my hobbies revolved around lapidary, polishing stones, silver work, enamelling, rock or wood carving, also weaving. But advancing years, cataracts and lack of machinery have made me change my options.

  I hope there aren't too many grass seeds in the rug. I try to get them all out, but they lie flat in the wool and get missed only to work out later."

  You will all be able to see this lovely rug in May - one way or enough it will be warming someone's knees by the end of the day!

- You may recall that the Summer 1993 edition of the Network's Information Bulletin included an article entitled "Just to See a Panda?" by Dorothy Gowen (a member of the Southern Alberta Post-Polio Support Society, Canada). The following article in response, entitled "**A Defence: I don't want to see the pandas either**" was written by Ruth Crowder of the Coffs Harbour Support Group.

  "I found Dorothy Gowen's article "Just to See a Panda?" printed in the Post-Polio Network Information Bulletin painfully thought-provoking. I remember, with shame, the many times I harshly refused the offer of a wheelchair so that I could see the "pandas". I remember the anger and sadness that these kind offers evoked. How could anyone who really loved me ask me to step back into a wheelchair - the very symbol of everything I had fought so hard to overcome. With hindsight I know that if I was as strong as I thought I was and had really overcome disability in the wider sense I would have accepted the thought and caring offer.

  As an excuse I offer this explanation. I think that the angry reaction is partly the fear of slipping back and the fear that one day, as I grow older, I may need to have a wheelchair all the time. I admit that my desire to be independent, and prove it, is over-riding and causes difficulties for me as well as the people who love me. Is this the price we have to pay? Dorothy Gowan makes the point that we share our concerns and problems with the Polio Network in an easy exchange of ideas but do not with our nearest and dearest. Is this because they were not there when we contracted polio - were not there when we fought our way back to a life as normal as possible? Were they just presented with the finished article and we cannot (or do not want to) share that with them?

  When I contracted polio in 1943 in South Africa little was known about it. It was called "infantile paralysis". I do not remember ever being given a prognosis, or an explanation of the virus, what long-term effects there might be, or even how to treat the resulting condition. I did not know anyone who had polio so it was a rather lonely time and survival my all pervading ambition.

  I agree with Dorothy that because initially we had to try so hard, this has become a way of life and affects everything we do. Asking for help or dropping our self-imposed standards is very hard to do.

  I appreciate her reference to her husband Bob being kindly turned away when he offered to help in preparing a dinner with a post-polio group. I too decline help in the kitchen because when I am cooking I have to think about what I am cooking, keep my balance and know that when I turn round or move there will be a clear space to put my hand down.

  Dorothy asks why we behave in such a contradictory manner and asks for answers. My answer is, there are no answers. We cannot change the way we are because it has been our way to survive.

  Let me end with a story that perhaps says it all. At a dinner party last week I was asked by a fellow guest how old I was when catastrophe struck. For a minute I did not know what she meant and I could only think of the time I dropped a raw egg on the carpet.

  A challenge yes, but never a catastrophe. I rest my case. **Ruth Crowder**