

## **X. QUESTIONS AND ANSWERS**

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**Question:** Do you know why purple feet feel better at sea level?

**Answer:** Frankly, this is the first time I heard that purple feet feel better at sea level. It may be that they not only feel better at sea level, but if you were under the water they would feel even better; and I say that not entirely facetiously. Given that compression stockings or support hose like Sup-hose, and the counterpart for men, can help with this condition, it may be the surrounding atmospheric pressure which makes you feel a little better at sea level than up in the mountains. In addition to the compression stockings, I think that keeping your body parts warm, e.g. wearing a woolly sock or leg warmers (which are "in" with people who are doing exercise) helps to maintain your body heat.

**Question:** It takes all my energy to work full time and to look after my family. I already seem to be working at my maximum. How do you incorporate exercise on top of it?

**Answer:** I hear this more often that I would like. When I am advising you about an exercise programme, obviously all this has to be individualized and incorporated into your particular life style. You can't exercise without conserving your energy. If you conserve your energy without exercising, you will become de-conditioned. If you do it the opposite way, you can cause yourself to be unduly fatigued and then you spend the entire weekend recuperating for work on Monday.

**Question:** Who in B.C. does a thorough assessment? Are there specialists in the lower mainland who specialize in post polio? Where can I get a proper assessment done? How do I organize myself to be assessed?

**Answer:** To be assessed, you want to have a reason to be assessed. Referrals should go through your family practitioner. Now as to where to go, that is not easy. You may want an expert to come and advise you. It may be that your brace is no good, so you may want to bring your orthotist in as well. Some of

the gadgetry and aids that you are using to help to get around may be improved, so you may want to include your Occupational Therapist.

As far as exercising is concerned, I have two physiotherapists in my group who assess patients, and decide on what they need. Some patients just need energy conservation; some of them need an exercise regime; how tough should the regime be? It is a team business, therefore there are very few individual physicians to whom you can be sent. You really need to go to a rehabilitation centre and, to the best of my knowledge, there are only five in the province. There are two in Vancouver, one in Kelowna and two on Vancouver Island. That is really where you need to go, that is the direction, but please, get a referral through your family practitioner. Nothing but harm occurs from short-circuiting the process, because you miss out a valuable link in the chain when the Doctor who treats you regularly, doesn't know what is happening.

**Question:** What is the difference between degeneration and arthritis?

**Answer:** Well, arthritis refers to the inflammation of a joint, whereas degeneration, if you like, is a change that occurs with ageing. Doctors also talk about degenerative arthritis and what does that mean? Well, that means an inflammation of the joint due to aging, so the two can be linked. When you hear about lumbar disc degeneration, which is what somebody may be thinking of here, the disc has narrowed, the bones are closer together and the two joints of the back are now overriding and you can get an inflammatory change. So, degeneration and arthritis frequently, but not necessarily, do go together. The best treatment is to know exactly where the degeneration is and where the arthritis is and to deal with them separately.

**Question:** Do the benefits outweigh the treatment when I get physically exhausted, or rather totally exhausted from exercising in a hot pool? Is it normal to also become mentally exhausted?

**Answer:** Yes, it is; if you are really exhausted. Have you ever seen a marathon runner at the end of a marathon race? He doesn't know which end is up or which way he is running. When you are really exhausted physically, and post-polio people can get totally exhausted, you can get totally confused as well. So that is not unusual. Exercising in the hot pool can leave you totally exhausted. What the question doesn't ask is - do they feel better generally or is

this just a masochistic thing they are putting themselves through? Should they be doing only twenty minutes per day and seeing if they feel better? These are questions that I would ask. Is thirty minutes maybe too much? Twenty minutes may be better. If they feel a bit better at twenty, then maybe fifteen minutes is better still. So in all seriousness, if that exhaustion lasts a few days, that is fine. But if it continues week after week, you are doing too much. It is fairly straight forward; you can work out your own regimen or routine better than we can. I wanted to emphasize earlier in the session that these are just guidelines to follow when you are exercising.

I think it is important to get an individualized or customized programme with the guidance of a physical therapist as I mentioned. If you are going to exercise on your own, use the rule that you should quit if something begins to hurt. You are abusing a joint, or if you feel a sense of fatigue or tiredness in your muscles, then you are overdoing it. Quit if you feel either pain or fatigue and think about pacing yourself when you are exercising. You have got to pace yourself at slow intervals and if you can do ten laps, then do one lap and rest for a few minutes before you even think about going on. There is a fine balance between therapeutic exercise and abusive exercise. So, remember if your are fatigued, right there is the warning signal that you should quit, you should back off.

**Question:** What do you do when the local general practitioner tells you that there is no such thing, but I need help with my problems?

**Answer:** Well, Dennis has kindly passed me something, if you will all write this down. In Family Practice, October 14, 1989 issue, there is an editorial on monitoring post-polio syndrome in family practice. I think perhaps G.P.'s would do well to have a look at it. I don't think that it is acceptable just to let it pass.

**Question:** Some of us survivors have had great relief from acupuncture. What are your experiences with acupuncture? Would you encourage the use of acupuncture?

**Answer:** For one, I am delighted that you had the relief from it. My experiences with acupuncture are has been good in part - I have had some very

good results; and would I encourage it? I think there are a lot of things in medicine that we don't thoroughly understand.

**Question:** What were the two drugs Dr. Cashman mentioned yesterday to be given in small doses for the treatment of insomnia? Spell them please, and what, if any, are the side effects, etc.?

**Answer:** He mentioned, as Dr. Galvon did, Elavil in a small dose, or Ametryptoline which is used for minimizing the discomfort of fibrocyclic or fibromyalgia of chronic aches and pains. It has a side-effect of being slightly sedating so that it can help people sleep at night. I don't remember him mentioning a second drug for sleep specifically or insomnia.

I was going to add a little more information on drugs and that is - some of my patients have told me that after an active day, it doesn't matter whether it is after a fairly vigorous day or not, they twitch when they lie down to go to bed at night; their legs twitch, or their abdomen twitches. This is called fasciculations and I am not sure whether to regard it as a warning signal that you are overdoing it or not. It seems to correlate to a degree with level of activity, but in some cases it does not. Some people just twitch when they lay down for the first fifteen minutes or so and they find it annoying. When I published that little editorial in JAMA that you all got a copy of, I got a call from a general practitioner in Texas who had polio when he was a kid. He told me about Omega 3, a fish oil, for twitching. Omega 3 is supposed to bring your lipids down. The point was that he had tried it on a few patients for their coronary artery disease and he took it himself and noticed that his twitching was less. Subsequently, I tried Omega 3 on a couple of patients and they have told me that it didn't make too much difference; but it is something that doesn't have a lot of side effects and you may want to try it. I don't even think it requires a prescription. You can also eat mackerel.

**Question:** It was gratifying to hear you, as an M.D., say that Chinese acupuncturists, who may have practiced for thirty years, were okay - I wonder what they would say about you, with your limited training in acupuncture?

**Answer:** Being diplomatic, they would probably say nothing. But I read something in an introduction to a book that went like this. "Me practicing acupuncture is a lot like a traditional Chinese doctor up in the hills coming upon

a case of Penicillin that had dropped out of an airplane and got lost. With the Penicillin there would be a little manual indicating its use for fever and sore throat, and some simple infections. He would give his patients a shot of Penicillin, and would probably be known all around that area as the most brilliant physician that there had ever been. He wouldn't understand Penicillin, but if he used it strictly for the conditions that he read about in the book, he would probably do a very good job of helping people. That is how I think I am practicing acupuncture - like that little guy in the hills is using Penicillin.

**Question:** How does acupuncture differ from acupressure?

**Answer:** Well, acupuncture uses needles. You use the same points in acupressure as in acupuncture. I think that acupuncture is just a little more elegant, although it is confined to people who are licensed to stick things in the body, whereas acupressure is available to physiotherapists, massage therapists, etc. A lot of physical therapists are actually taught, or can take courses in trigger point acupressure. They are working on the same points as acupuncture and it probably works quite well.

**Question:** Is there a cumulative effect to acupuncture? Is it an ongoing process?

**Answer:** Both. If used at, say no greater a frequency than once a week, by the time two weeks rolls around, I think you probably have lost any cumulative effect. If you have a second treatment within a week or less, I find that there can be a cumulative effect to it. In the hospital-based acupuncture clinics they will treat you ten times over two weeks, and that is a course, according to Chinese theory. With ten or twelve treatments - virtually every day or every other day you are expected to improve and then you just go on - that is the cure. I treat at weekly intervals just because that is what is practical in an office setting. In four to six weeks we have our effect and you will come back probably at monthly intervals.

**Question:** Has acupuncture ever been used to help a limb with poor circulation?

**Answer:** Yes.

**Question:** If it can, would it be long lasting or would it have to be continuously kept up?

**Answer:** I have a funny story - a lady came in to see me complaining of cold feet. She had had health problems but had cured some of them through the wonders of macrobiotic diets - fish oils and mackerels etc. Her feet were cold and her husband hated it. It was affecting their marriage and their life. I told her to eat liver. But, as she wouldn't eat meat, I suggested acupuncture. I did acupuncture on her two or three times over a couple of weeks. Then she came back and said, "I've got another problem now, Doctor." When I said "Well, what now?", she said "My husband hates it because now I throw the covers off my feet because they are so hot at night. So can you turn them down a little bit?" So I don't know, I think I did backwards acupuncture on her or something to turn them down.

**Question:** Is there any benefit from exercising in a warm hot tub? - how frequent and for what length of period?

**Answer:** Well you know, since I am from San Francisco, I am right next to Marin county which is the originator of the concept of the hot tub and the peacock feather. So I am eminently qualified to answer this question on the benefits of exercising in a warm hot tub. Well, you can't do laps, that's one of the disadvantages. You don't want it to get too warm, I think is one point that I want to make. The buoyant effect of the water eliminates the effects of gravity and unloads your painful back or your painful knee, whatever it happens to be. If you can stay in, again keep the temperature down below 100, for about 20 minutes, it can really help with general pain relief. Then you can begin a fairly vigorous stretching programme and flexibility exercise programme for your limbs, for your back, trunk, and so on. I think a hot tub, with or without peacock feathers, is a great way to exercise. We are going to propose a Bay area versus Vancouver, with and without peacock feathers study here.

**Question:** What can be done for poor circulation in the legs?

**Answer:** Well you have just heard that acupuncture can be of some effect. I think it depends on what you mean by "poor circulation." I have a number of

people who have come to me complaining of poor circulation. What they mean is - "the purple feet syndrome" that I talked about yesterday, or sort of a cutaneous vasomotor dysfunction. This is the inability to shunt blood away from the skin, down deep, and so that there is that radiator effect with loss of heat. It is not really an artery problem. Compression stockings and keeping your feet warm and wearing good woolly socks are important. Up in the northern climates where it gets to 40 degrees below zero and affects micro-chips and is incompatible with life, I think you need to wear lots of woolly socks.

Finally, some people have complained of poor circulation and in fact, what they were referring to, was the sort of leg pain that was associated with spinal stenosis. That is to say, it is really a neurological problem, it's not a blood vessel problem but it sometimes feels the same. People sometimes think that they are getting claudication pain or pain in their calves that comes from exercising, thinking that their circulation is poor. It really is a problem of the nerves being choked and that the legs start to hurt after a period of being up or walking a little bit. Of course, as I said, polio folks are not immune to other problems and you may have just poor circulation in your legs because of peripheral vascular disease - from smoking, from your age, from the genes you inherited that tend to build up a little cholesterol or whatever. So, eat mackerel.

**Question:** Why do post-polios feel better at sea level?

**Answer:** I think yesterday I said there actually is a phenomenon that has to do with the oxygen pressures if you tend to have some breathing problems. In fact, one of my patients, Father Lewis, who is a chaplain at St. Mary's, was a polio survivor who was in an iron lung for a while and hasn't been using one for years. He went on an airplane trip in an unpressurized plane from San Francisco to Lake Tahoe and it threw him into congestive failure. He had some little strokes - tiny little ones from the tension of oxygen not being adequate because of his marginal lung capacity. So that there may be something to that, if you have marginal breathing. Now on the other hand it may have to do with if you live in the hinterlands and you go to the seashore. It may have to do with the vacation aspects that make you feel better and have nothing to do with your breathing capacity or anything else.

**Question:** Why do my legs go numb when I walk, after four blocks, in the afternoon?

**Answer:** Again, it could be related to spinal stenosis - that choking of nerve roots from too much arthritis in the back that can happen to people over the age of sixty. It is not exclusively a problem with polio folks but I think that some older polio people are more susceptible to getting excessive arthritis in the back. This can choke things or it could be a circulation problem and it also depends on what you mean by "numb". Some people mean, when they say "numb," a sort of pins and needles feeling. Some people mean truly numb in the sense of anaesthetic; or pain and that they are having some discomfort and they refer to as numb. To be specific and answer the question, it has to be individualized.

**Question:** Also, would you recommend estrogen patches for us as we age to help with osteoporosis?

**Answer:** That is a good question. I think that this is my own bias, that polio survivors, men and women, who have weakness in a particular limb, are susceptible to osteoporosis. Women who are post-menopausal are susceptible to osteoporosis, whether they have had polio or not and should have their estrogen checked. This should be talked over with your internist or your family doctor. I would strongly consider being on estrogen for the positive effects, not just for osteoporosis. So I am an advocate of estrogen where it is practical and safe to do. But it should be carefully monitored by an internist or your family physician.

**Question:** Please discuss the impact of deconditioning on fatigue and the amount of rest/sleep required.

**Answer:** I can't refer you to any scientific studies that have to do with the effects of deconditioning on sleep requirements for able-bodied people. That is to say. people who become deconditioned have multitudes of side-effects and those include insomnia, sometimes a little depression, and slight demineralization of the bone which elevates the calcium floating around in the blood. It can certainly affect circulation - and it can affect constipation. There are many problems associated with deconditioning, so I think that the better condition you are in, the better off you will be. That has to do with exercise, nutrition, and the avoidance of toxic things like nicotine, alcohol and other drugs. All of that can have an impact on your sense of health and how well you

sleep and so on. So, yes, it can have an effect on your sleep, quite apart from any other aches or pains.

**Question:** What is the effect of hot tub jets on neck and shoulder muscles and joints?

**Answer:** I think essentially for that vague, aching pain, where you have muscle contractions, warm water is good. I should warn though that if you have got a swollen, painful hot joint that heat is contra-indicated and usually icing is better because what heat does is it increases blood flow and that is contra-indicated where you already have a lot of blood - too much, in fact - as in a hot, inflamed joint.

**Question:** Can this type of massage been harmful?

**Answer:** Other than what I've said, I think it is a good modality.

**Question:** What effect does climate, like cold and damp, or warm and dry, have on post-polio survivors? Is it better to live in Arizona or another desert state during the winter?

**Answer:** Well, sure. I think it is always better there. That applies to anybody. You are the best judge. It is probably a function of your general health - your respiratory status, of how you feel in different climates and I think probably there is no blanket answer here and each individual will find the climate that suits them better and if they have the wherewithal to go during the winter to a different climate, I think that will help. I would recommend Hawaii over Arizona.

**Question:** What are the risks involved in anaesthetics, and should post-polio victims have anaesthesia for dental work?

**Answer:** You should always tell anybody that contemplates giving you anaesthetics that you had polio - that goes without saying. And I think the risks there are the risks of anybody that has any type of respiratory compromise. I don't think, to my knowledge, that the anaesthetic itself will affect your neurons

and make them progressively weaker after the anaesthetic. But I think there are risk factors of anaesthetics as it applies to the depression of the respiratory system - so I think that is most certainly a risk and you need to tell your anaesthesiologist that you had polio and need to have a respiratory evaluation.

**Interruption:** I would like to interrupt with something that I feel is extremely important in that we are so much more sensitive to drugs. When I was given novocaine at the dentist's office I fell out of the chair with almost cardiac arrest symptoms. It is important for us to remember that.

**Response:** Right. I am sure. There are recorded cases of people having weakness - that sort of affect - after getting an anaesthetic and some people need to be tested prior to anaesthesia. So I think it is important, if you have concerns, that before you have any sort of anaesthetic-related surgery that you go over this very carefully with your anaesthesiologist. Thank you for making that point.

**Question:** Is there any published information about swallowing?

**Answer:** I have noticed even in the small number of polio patients that I have seen that a lot of polio patients don't really complain often of respiratory complaints. If you go and have respiratory evaluation you find that, in fact, there is compromise. It is just that we are good at compensating for that and unless we are put into a stressful situation we don't know that we have compromise. I think the same thing applies to swallowing. Unless you purposely ask and really try and bring it out, you may not hear about it. I now purposely ask for it because I have a method of testing to see if there is weakness in the oral phase of swallowing. There are some published articles on oral phase swallowing difficulties in people with polio and this is now becoming an increasingly important area to research. Hopefully we will be able to find out ways to help people that do have these sorts of swallowing problems.

**Question:** What is CARTEL?

**Answer:** Cartel is an acronym. I started a conceptual model in Victoria and we couldn't think of a name for it. We decided to describe what we intended to do and we formed the first letters to make the word "cartel". Cartel is the Center

for Assessment, Rehabilitation, Training and Enhanced Life Styles. What it is basically is just a multi-dimensional approach to a variety of health problems. Our primary business is physiotherapy and rehabilitation.

We do a lot of measurement work; we have done a number of applied research projects, of which the very small project we did with the Post Polio Society was one of them. We have done two others - one was involved with the senior management of the B.C. Government in a health risk reduction study. We tried to take all the deputy ministers and all the assistant deputy ministers from the provincial government and assess them in terms of their risk state and try to get them to live a little healthier life style. We tried to decrease their risk and make them more productive over the long term. That is we didn't want them to have heart attacks, etc.

Another study we just completed for Forestry was - we went out and measured the fitness capabilities and performance capabilities of the forest fire fighters. That is the kind of thing that we do.

We deal with a lot of individuals who come out of post-surgery, post-injury or chronic conditions and we help them in physiotherapy. We assess them and then treat them in a long term rehab section.

My expertise is more in exercise physiology. We deal with people in more traditional training methods and this is what intrigued me about the post-polio people. You couldn't really apply traditional training methods to post-polio people because "more was not better - more was worse". You have a real problem with this group. You talked to twenty different people, they all have twenty different symptoms that manifest themselves in different ways and then you have to individualize the protocol.

I think that is what I meant about searching, in that every post-polio person seems to have to go through trial and error in trying to find the things that work for them. We need to do a lot more research and work to try to find some ways that we can improve the quality of life for post-polio people. That is what Cartel is and we hope that we are going to be able to do some more work in this area with the muscle stimulator.

We need a lot more subjects and we need to try some different things like different lengths of time, different kinds of protocol with regard to the types of stimulation. So there is a lot of work yet to be done. I would really like to get

the opportunity to do that if we could. I think the method may have some promise and that is all that we can say about the project to date.

**Question:** Would you call what you do acupressure or 'touch for health'?

**Answer:** First of all, acupressure is dealing with meridians and energy flows, this type of basis. Myotherapy bases each and every treatment on your particular life. The maps that we do of each person is your life. We work with every muscle from head to toe, without using energy flows, not that it is wrong, it is just not our approach. The only similarities is the applying of pressure. All muscles attach at a specific place and end at a specific place and they also have a body - we work with the entire muscle. We deal a lot with corrective exercises and to my understanding that is not dealt with in acupressure or acupuncture. As for this touch for health - I don't know what it is so I can't really compare it.

**Question:** Does B.C. Medical pay for visits to a myotherapist?

**Answer:** The answer to that is no, not in Canada. Myotherapy has only existed in Canada for a little over a year. The only thing that covers it at this point is ICBC. So unless it was an accident of some sort or you work at a specific plant like in Quesnel, where those particular mills will cover you if that is in their plan, you are not covered. It is up to the individual company whether or not they cover you. We try to make the payment plan as easy as we possibly can. On an average most people do require five treatments and with five treatments in mind, it comes out to \$315.00 for the five treatments. Each treatment is an hour in length. The first treatment is an hour and a half and we will train you how to continue your own myotherapy. Our objective is to see you well and on your way, not returning to the clinic, unless of course you want maintenance.

I think I should mention something about the tools which we use. Some people live alone and they don't necessarily have anyone to help them with the myotherapy or it may be inconvenient to have someone else to help you with it. Bonnie has come up with this tool and all it basically is, is a little wooden dowel. I encourage people just to use the end of a wooden spoon, it basically works the same. You are eliminating trigger points by applying pressure to a trigger point. Hold each trigger point seven seconds throughout the body, five

seconds in the head area. Be sensitive to your trigger points. If you are working on someone else, certainly be sensitive to them; apply pressure slowly in, slowly out and maintain the pressure. This is used with people who have rheumatoid arthritis or a handicap of some kind where they cannot use their hand. So this tool is what we use to the hand, to the shoulders, to the arms, whatever area you are working on. I have had patients go and buy a cane and use the same thing. The diameter is not the same, but it works just as effectively. This is how it works, you just apply the pressure to wherever the area is, shown on your charts. You know where to go, it is not a guessing game. After the fifth treatment you have a pretty good understanding of where your trigger points are going to be or I have a good understanding of where your trigger points are. I have eliminated a great percentage of them and mark whatever is left in the body or what the major trigger points are.

**Question:** If the myotherapy proves to do more harm than good, what recourse does the patient have?

**Answer:** The absolute worst that myotherapy can do to you is cause a bruise - that is the worst. You can break a rib if you try hard enough. A myotherapist increases your circulation, so if you have blood clotting in your body it could naturally kill you. We will not touch a patient unless they have a medical doctor's referral and this medical doctor has stated that it is a muscle problem. Regardless of which disease - if it is post-polio, if it is spasmodic torticollis, it doesn't matter what the disease is, if it has affected the muscles, then we have ruled out any possibility of any problems. If you go to a therapist who claims that they are a therapist and if they will take you without a medical doctor's referral, you should be skeptical. They should have credentials on the wall and they should be certified. If they are not trained by Bonnie Pruden, be skeptical. She is the founder, so it is up to you to be careful of the therapy that you go for.

**Question:** Do you have any valid certification within our medical system?

**Answer:** There is no one in Canada that knows how to do myotherapy or has any background in myotherapy. Therefore, there is no testing that could possibly be available. My training is done extensively in Massachusetts and New York. The Board exams are done in Stockbridge, Massachusetts - that is where the training is done. Recertification is done every two years. You must

maintain your certification; that is why it is important to make sure these people have their certification with them.

**Question:** I have a severe ringing in both ears; what can I do to help?

**Answer:** If the trigger points are maintained in the muscles lining up to the ear, shoulders, upper back and neck they are in spasm, they are in tension. You have to relieve those muscles, re-educate them through corrective exercises and by doing this, release the pressure. Now there are no guarantees in anything, which I am sure you well know, but the books are available. Certainly try to eliminate these points on yourself and if you get the slightest amount of success then you know that you could get so much more. Remember the exercises are absolutely crucial. If you have any questions, you can call me at any time, if it is as basic as an exercise or something a little more on the myotherapy. Certainly contact the local myotherapist. If you write to Stockbridge, Massachusetts, to the founder of the organization, she will give you a mailing list of all the therapists that are throughout the United States and Canada and let you know who is the closest to your area. They will be more than happy to answer your questions.

**Question:** Would it not be more appropriate for you to talk of ways to improve our quality of life through body supports, etc., rather than talking about asking us to lobby the government for improvements to medical insurance, medical services plan, etc.?

**Answer:** I am glad that this question came up because it is a difficult thing that is never discussed. People with cerebral palsy, people with spina bifida who are growing up, incidentally, are all facing the same problems. Parents who have children who are growing out of braces every four to six months face incredible costs and for the most part they are not covered or they are only partly covered. I see patients that come into my office who require orthoses and the cost of these is a hardship for them. A lot of people do without. I had a gentleman who came into my office about a month ago and I did the final fitting of a long leg brace for him. The brace he came in with he had been using for 35 years. Needless to say, it was shot. I made him a new appliance after taking a plaster cast, which is the normal procedure, to get a positive shape of his limb. Now very crudely I took a bathroom scale and weighed the differences between them. The old device that he had been carrying around for 35 years weighed

something in the neighborhood of 12 1/2 pounds. The new device was 3 1/2 pounds - a savings of nine pounds. Now 3 1/2 pounds is still pretty darn heavy.

**Question:** What is the benefit of this technology?

**Answer:** Well, one of the benefits right off the bat, as I can demonstrate with this gentleman, was weight reduction. The interesting thing about it is that it has an accumulative effect and especially with post-polio. If a person walks an average of 2,110 steps every mile; in one year, walking three miles a day (now that may be a little bit high for polio victims) with a 13 1/2 pound brace, you are picking up 14,000 tons. With a 3 1/2 pound brace you are picking up 4,000 tons of weight. Now that is not an expression of work - it is also a useless number but I just mention it to demonstrate to you that there is a tremendous amount of work involved in using this. Not only that, we are dealing with somebody perhaps who can't move their ankle or they can't move their knee. The design of the brace is such that it has to lock that up. Now you have to overcome not only the weight of this device now, you have to overcome the fact that these joints do not articulate. If you study biomechanics you see that requires an incredible amount of work.

So the whole point was not to be self-gratifying here and to use you as tool with the British Columbia government. There is a great need and there is technology available. The funny thing of it is that we are starting to see the technology being used in other areas and other ways. for example, this blue device that you see here, it is not for a polo victim. It is for a person perhaps my age, who has gone out and sustained an injury to the knee and may have had surgery to it. This thing weighs 13 ounces. There is greater technology available than this and there are a lot of businesses producing and working on solving problems associated with this kind of sports medicine problem. They are not doing it with polio. It is extremely labor intensive and you couldn't afford the technology, you shouldn't have to afford the technology. You have a legitimate need and so do a lot of other people.

If you look at the war amputees of Canada, for example who have done a tremendous job of lobbying. There are not a lot of them now, but because of the strength of their organization you probably have all heard of the Champs Program. Children who are congenital amputees, which is a fairly large population, are benefitting from their efforts. You can do the same type of thing.

Keep in mind you suffered from a virus which attacked society and society went into a tailspin over this virus. The fact of the matter is, as was said yesterday as well, viruses are a very popular thing in the news right now. But we haven't really grasped the significance of this virus. The chances of a virus hitting society again that will affect people in the same manner that polio has is very great. There are people every day that have an unidentified virus that end up with the same type of effect. So there is a beneficial spin-off for everybody, paraplegics from traumatic injuries as well as children with spina bifida. For example, they didn't live fifteen years ago, now they are living and they are growing up. There is some coverage for their bracing. Once they reach age 18 - "Sorry, Sunshine, you're all on your own, we are not paying for a thing." So that is why I brought it up.

One of the Physios here asked me - "What is the latest in long-leg bracing and what can it do for severe hyper-extension?" A very valid question because hyper-extension is a problem that polio victims face quite frequently. Very often we all ignore them because they are a difficult problem to overcome. What we do when we hyper-extend our knees is we set our center of gravity ahead of the axis of your knee and in that way you can stand. Your knee stays in extension and locks because you don't have the muscular strength to hold yourself up. Over a period of time, over years, what happens is that we start to stretch out the posterior element of your knee. Then what happens is the problem starts to accelerate and then it accelerates at an exponential rate. What I mean by that is, you have managed for 10 or 20 years and your knee is hyper-extending and perhaps don't even notice it. It seems to be getting a lot worse now and in fact, you are having a lot of pain. The deformity is marching along at an incredible rate.

Now to answer the question - as far as bracing is concerned, what you have to do in the case of severe hyper-extension, is you have to make a brace for the whole leg. The reason is, because you have to distribute the forces, the load, over as long a lever as you possibly can. We use what is called a force couple, that is, you have to have two forces anterior to the leg and distal. That means as close and as far away from the knee joint as possible; and two other forces posterior, close to the knee, so that is a forced couple, to try to stop it. You shouldn't eliminate hyper-extension, you should control hyper-extension. Because if you have muscular weakness you need some hyper-extension to stand with stability. You don't need a brace to have ten degrees of hyper-extension

but is not allowing the posterior aspect of your knee to be stretched out. I think that answers the question.

**Question:** Frog breathing - how is this done?

**Answer:** We will move through this one quickly. Frog breathing is used for post-polio survivors who are paralyzed from the neck down. It is difficult to explain but what they do is that they use their tongue to swallow air into their lungs, rather than their stomach. They use this as a way of breathing when they are not on a mechanical ventilator of some kind and then when they fill up their lungs with air the natural elasticity of the lungs allows them to collapse and the air comes out. It is something that if you have progressive respiratory disability, as a result of post-polio, that would be a good thing to learn to do and it is really quite an art. There are some excellent frog breathers the best way to learn is from someone who has already developed the art of frog breathing and can teach you.

**Question:** In generalized paralysis, is swallowing reflex and trachea weakness a condition of post-polio syndrome?

**Answer:** In any neuromuscular disease a swallowing reflex can become a problem if it is a progressive type disease. That is something that can be a problem with post polio that you may not have had in the past.

**Question:** Is diaphragm weakness and chest muscle weakness connected to hiatal hernia?

**Answer:** I would have to say "no" on that. Hiatal hernia is a condition that is characterized by a certain amount of pain and is involved with a part of the stomach, It actually comes up through the hole in the diaphragm where your esophagus is supposed to go and that is what causes the pain. It really doesn't have anything to do with muscle weakness although it could be aggravated by muscle weakness.

**Question:** How does the patient in the outlying areas of B.C. get the sleep test?

**Answer:** If there is a respirologist, which is a pulmonary specialist, a chest physician, in your area, he can probably make arrangements for that. If not, your family physician can probably arrange to have you referred to a respirologist, if you are not already seeing one, and he can make arrangements to have the modified sleep study done in your home. This is by no means the same test as what is done in a complete sleep lab such as is at U.B.C. and in some other facilities. This is a very modified test that is done in the home and that is simply geared towards identifying that there is definitely a problem and you need to be investigated immediately.

**Question:** A new and traumatic problem is almost immediate breathlessness which quickly curtails any further exercise, housework, whatever. How can one train to improve?

**Answer:** I think you mean shortness of breath - immediate shortness of breath. If you are experiencing immediate shortness of breath, it sounds like there is a problem with your respiratory system and you may need to be on low level oxygen therapy. It is something, again, to be investigated by either your family physician, who would probably refer you to a pulmonary specialist.

**Question:** For post-polio with sleep apnea, not severe, would oxygen while sleeping prolong the advancement and enable a patient to sleep through the night? Once you have sleep apnea does it ever go away?

**Answer:** There are different causes of sleep apnea, some of them are neuromuscular diseases. Those are not usually reversible. Other causes of sleep apnea sometimes have to do with a certain amount of obesity. These are associated with severe snoring while sleeping, which is usually one of the symptoms of the sleep apnea. These conditions can sometimes be relieved with a weight loss. Actually most of these people who have that type of sleep apnea do not go on a ventilator. They are hooked up to a small unit that is connected to a nasal mask. It provides a flow of air which helps keep the soft palate at the back of the throat open and solves the problem that way. So if obesity is one of the primary causes and the weight is lost then certainly the sleep apnea would be resolved.

**Question:** What facilities for post-polio people are available at George Pearson Centre?

**Answer:** There are a lot. Being manager of respiratory services and being relatively new there, I couldn't possibly list all of them. We have the Pearson Achievement Centre,- we have a very large education and training department and different activities available. We are basically a resource centre for post-polios and other people with physical disabilities. Please do not hesitate to call us if you are interested in finding out what sort of programmes we have that you might be interested in.

**Question:** What can one do on their own regarding a sleep problem, whereby one gets three or four hours of sleep a night. Muscles ache unless one uses sleeping pills?

**Answer:** I don't think that this is really a question that I can answer. If you are not sleeping due to pain, then it sounds like the pain needs to be dealt with. That doesn't really sound like a sleep apnea problem.

**Question:** How do you reconcile energy conservation with weight control?

**Answer:** It is something that is difficult, I realize that, and I think you have to balance your exercise and your diet and do the best you can. You are not the only ones who have that problem.

**Question:** If muscle strength is good, do you do more exercise compared to someone whose muscles are weaker? If so, how do you know you are not doing damage?

**Answer:** I am not sure what you mean by "good". Does that mean that there is normal muscle strength or that there is some weakness and still fairly strong, or at least functional? I guess I would answer that by saying that if you were still fairly strong, I would still follow the same protocol. I would still cut down and start on a very sub-minimal weight resistance. If you have fairly good, strong quadriceps, then you probably - if you were tested on the Kin Com - are going to be able to resist quite a bit more than a lot of our patients. I mean they could maybe resist six pounds which is not very much. I would still follow, basically,

the same format but remember that format is not written and if you still are not fatiguing, then go ahead. It is just a guideline and you are going to be self-monitoring so you know whether you are doing damage. If you are fatiguing, you have less energy, you have to cut back.

**Question:** Do you include proper breathing techniques in your no-fatigue regimens?

**Answer:** I would say, "yes", and I also teach modified yoga techniques where it is appropriate. Again, we really tailor the programme to the patient. You are all different and we just have to tailor it for your needs.

**Comment:** I have been doing yoga with pranayama breathing for several years and have found it to be quite beneficial. The proper breathing techniques improve my everyday energy level, as well as the stretching benefits of the yoga postures.

**Answer (contd):** I have found that yoga is wonderful for some people and not good for others and Tai-chi is wonderful for some people and not for others. It is just what suits you, and I am very glad this person has found this pranayama breathing and the yoga concept is very good. I think Westerners have a great deal of difficulty with the yoga concept because they tend to push themselves and then yoga can be damaging. If you go by the Eastern premise that you don't push yourself, you are okay.

**Question:** We have been advised to use 5 to 8 lb. weights at home for lumbar traction. Due to one hip being higher than the other, it causes pain in the leg adjacent to the high hip, although the spine feels better. How do we alleviate the problem?

**Answer:** I am not terribly sure how you are going to alleviate the problem, except that I do know in our department, we have a home traction where we just put the traction on one leg. I am not sure how your home traction is set up but I know some of the therapists are having difficulties with their backs. when I went upstairs the other day, there was one lying on a traction table and it was a home device. The amount of weight is just water in a bag and it is just attached

to one leg and hangs over the side. That kind of a system might relieve the pain in the other hip, as well as the back.

**Question:** How do you teach, or persuade, your local physiotherapist that polio is different from others needing therapy?

**Answer:** I apologize for those in my profession who are rigid. I suggest try saying to her "I went on a course and was told by a number of physiotherapists and doctors to do non-fatiguing exercise, rest, and conserve energy. What do you know about this?" That might help you, I don't know, try it.

## **XI. FINAL PLENARY SESSION**

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**Rheta Davidson**, President of PPASS of British Columbia:

I am very pleased this morning to be able to introduce Joan Headley from the Gazette International Networking Institute (GINI) of St. Louis, Missouri. I have always called GINI the mother of the Post Polio Network. Joan is the Executive Director of GINI and we are thrilled to have her with us today.

**Joan Headley**, Executive Director, GINI:

I would like to start by sharing with you a feeling I had the other evening - I'm not sure what day it is, so I'm not sure what evening it was! It was kind of *deja vu* from our Sixth International Conference in St. Louis last June. It was a difficult conference and people were coming to me and saying "Joan you did a wonderful job, the conference is great." You think `well, they are not going to say "This is the worst conference I've ever been to!" so in your mind you always wonder is it really good or are they just saying that.

I remember after the first day of our Conference I went up to (our late founder) Gini Laurie's room and she said: "Joan, this is just a wonderful conference and you're doing a great job." To this I replied: "Gini, what else could you say?" She said "Believe me, Joan, I know it is a good conference because everywhere I look I see smiling faces." I think you want to remember that, because, as I was sitting there at dinner, everywhere I looked I saw smiling faces. That is really, really important, and I think all of you who organized this conference should keep it in mind. It's really been an excellent conference and we're not just saying that because we are guests here. It really was. And it really is.

I do have several prepared things to say. I want to do two things today. I would like to explain the role of GINI in the "Late Effects of Polio" movement and I would also like to share some thoughts about the "Self Help" movement.

During the 1950 epidemics, polio struck thousands of people of all ages. With improved medical management, individuals including those with severe respiratory polio survived. To meet their needs the National Foundation for

Infantile Paralysis or March of Dimes created and funded sixteen respiratory centres around the USA.

The late Gini Laurie, our Founder, was a Red Cross Volunteer at the Cleveland Respiratory Centre Toomey Pavilion. Gini was born as a "replacement" child for two sisters who had died in earlier polio epidemics, so it was natural that she would volunteer at the Respiratory Centre. As a result of the successful vaccine, public funds dried up, the centres were closed and survivors sent home. After being sheltered from all financial worries, polio survivors (Gini's friends) faced extraordinary adjustments. Survivors needed support. Many of the centres published newsletters and held annual social gatherings.

Ultimately, all of the support from the original centres faded away except the Polio Survivors Association, still active in Los Angeles advocating for respiratory-dependent survivors, and the Rehabilitation Gazette, a journal started by Gini in 1958. Written by the alumni of Cleveland and other respiratory centres, it became the only national advocacy organization for Polio Survivors. It was designed to share information on do-it-yourself equipment, others' experiences and to support its readers. In the 1960's the Gazette discussed housing, employment, higher education, raising families, using terms such as "polio quad" and "respos". In the 70's the Gazette discussed the Rehabilitation Act of 1973, ALS, Multiple Sclerosis, etc. expanding its network to include all disabilities.

It was in the 1979 Rehabilitation Gazette that a letter by a gentleman from Arizona was published. He wrote "During the past few years I find myself being able to do less and less and tire far too easily. I have visited different doctors. To each doctor I was a strange and different individual because he was totally unfamiliar with Polio. They were all more interested in learning from me than giving me any worthwhile information. I would like to suggest that readers of the Rehabilitation Gazette, which seems to be the last polio link, submit names of doctors who are experienced and sympatico, to ease our transition into these passing years." Because so many people responded, not with sympatico doctors, but with similar complaints of tiring far too easily, Gini organized the International Conference on Respiratory Rehabilitation and Post Polio Aging Problems in 1981.

The purpose of this first biennial conference was: 1) To alert her polio friends; and 2) To inform and involve the medical community. The first meeting of 120 individuals in Chicago set the ground work for the important task of educating

health professionals, service agencies, the general public and polio survivors about Late Effects of Polio and was held October, 1981.

Rena Schneider and her caring Oakland physician, Dr. Stanley Yarnell, held an open symposium in Oakland on post polio sequelae. Dr. Yarnell recalls the collective "Ah, hah!" when Gini showed up at the Oakland symposium. In everyone's mind was "there really is something here" and it was very important to the whole idea and the whole movement.

The International Polio Network, coordinated by GINI, has been relentless in completing the important task of informing polio survivors and involving physicians. We continue to publish **Rehabilitation Gazette**, the **Polio Network News**, the **IVUN News** (for International Ventilator User Network), **Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors** and **Handbook for Ventilators & People with Muscular Dystrophy**. We continue to coordinate International Biennial Conferences. Our next meeting will be in June of 1991. We sponsor support group leaders workshops - the Third Biennial Leaders' Workshop will convene June 8th-10th, 1990 in St. Louis.

Let us turn our attention to support groups and support group philosophy. I would like to touch briefly on the statements of philosophy and offer some suggestions. I am intentionally going to say some things I hope will challenge you, that you can challenge me on, or have us think a little about support groups, their purpose, and support group philosophy.

People attend support groups because they share a common health concern. Polio survivors meet because of having had polio. It is not only easier to talk to someone who has had a similar experience but proves to be well worth the time and effort. Having had polio is the link. Survivors who had polio as an infant may want to hear about it and hear what it was like to have had polio. Those who were older at the time of onset may not necessarily want to relive it. Many polio survivors were taught never to discuss their disability and for obvious reasons, never to complain because "but for the grace of God, etc". Some individuals who embody a polio success story now need help, want to ask for help and need to feel okay about doing so. Some survivors have not been a success story. They have had a very difficult time over the last 30 years, some feel like a failure, and the thought of the late effects is devastating. Some survivors are in need of a secure place to express their fears and doubts about their life as a person with a disability .

A support group, and this is a really big task, should provide the environment so all these individuals can ask and receive help. Individuals who attend your support group are looking for people who really understand, who have been there and who are living examples of successfully coping with the late effects of polio. They come to seize control of their health problems and their lives. Support groups share accurate and specialized information.

Polio survivors, as all individuals with a problem, need information to make an intelligent choice. An uninformed choice is no choice. In general, support groups are good at screening and giving information. When members ask for information, listen carefully to the request. Confronters appreciate and even need a lot of information to relieve their fears. Avoiders need a small amount of information to assist them, too much information increases their stress.

A word of caution about information and literature. Please screen it carefully, be on the look out for quick cures and groups using polio survivors only to make money. Responsible groups seek out appropriate medical resources. I would encourage you to survey your community so you have medical resources available along with resources for shoes, equipment, medical professionals as well as financial assistance resources. Many polio survivors are completely new to the world of disability. They not only want information about the late effects of polio but about life with a disability.

Support groups provide non-judgmental support time and time again. People say how difficult it was to muster the courage to go to a meeting and then how they talked and talked. I think we've all been to a meeting where someone came for the first time and they just talked and talked. I would like to encourage you as veterans to remember your first time. Maybe you didn't react that way but maybe there has been a time when you did react that way. Please remember the first time and listen to all new members as if you've never heard it before. Sometimes it is difficult to do. A thoughtful nodding of your head in agreement can be very, very important. I have a lot of people call and say the first time they stood up and spilled their guts nobody nodded their head in agreement and they went home thinking I'm still all alone and I'll never go back.

Be open-minded, accepting, and non-judgmental. As veterans, you are examples of successful coping and your insight is needed and vital to the group. Be sure a member is ready to hear your solutions though, before you regale them with details of your story. I think that happens sometimes. One leader

says "I am compulsive about not telling people what to do" - that may be extreme. Another comment "Most people know what they need to do, the real issue is when will they go about and do it". Lastly, do not forget that some members will have problems that are beyond your expertise. You are doing the member and the group a favour by referring them to appropriate professionals.

Membership is fluid. Veterans will leave, new people become the veterans. People attend, solve their problems, regain self esteem and go on with their life. That's really what we want people to do. The ideal result is that they stay in the group for a period of time to assist newcomers, because self esteem is enhanced even further in an individual who was once the helpee and is now the helper. I believe we need to re-evaluate how we measure our success as a group. Somehow the value of one person with knowledge and experience assisting another individual in a similar predicament, on a very personal level, has been downplayed. You are an unequivocal success when you facilitate the person-to-person contact and please do not forget that. If membership is fluid, attendance then is more likely to be static than increasing. Leaders are frustrated by the vast difference in numbers on the mailing list and numbers in the meetings.

There are several reasons why people do not attend support group meetings. Many survivors want the information but truly get their support elsewhere, from their families, their church, other organizations. Many feel not enough is known about the late effects so why talk about it. I think sometimes when we get into so many different theories it does turn people off and they say, "if you don't know the answer, if you have nothing more specific for me, why should I come?" Many are not ready to share their deepest fears in public. They fear if they start talking, and it happens, they will lose control and control is what people are seeking. Many come and see people more disabled and feel they can not express their concerns. How can I explain about my big toe hurting when I see someone in a wheelchair or someone on a ventilator. They can't come, stand up and express their fears because there is someone that has got worse problems. I hear this quite a bit too, many people do not want to go.

Some groups don't like their leaders, see no sign of them giving up. I'll be really honest and this is rare. I don't hear it that much, but it is mostly because the job is really a difficult one. If anyone's willing to facilitate it and make it happen, not many people are going to be critical. I would suggest though that you listen to the criticism, see if there is any merit in it; if there is adopt it; if there isn't forget it. Some groups have individuals who take over every time and attendance drops because no one leaves feeling good. This may be the time

to strongly direct the individual to a professional. You have once again a responsibility to the group.

Support groups govern themselves, their agenda, and members feel that they own the group. Many self-help experts feel that ownership is the most important aspect of a successful group. A sense of ownership on the part of the members causes them to invest their time and effort to make the group work. If they perceive that the group is owned by someone else, whether a professional or an agency, they tend to step back and let the professional or the agency do the work. In a group, it is important to have a true sense of equality and mutual respect for each other's values and knowledge. Support groups need to think broader, be open to all types of programs and all types of solutions. Leaders of some groups appear to have narrowly defined what is right and what is not right for all. I have people say "Well, we don't believe that in our group." Someone comes with a concern and they say well we don't believe that in our group. That person is not probably going to come back. Some groups do shut out viable options. Support groups need to foster a feeling of community and belonging.

Offer a variety of programs and formats. Some of the most successful groups have such a very wide variety of programs and formats. You will then appeal to more of your members. Members need to feel in control and feel they have some say in the direction of the group. A non-judgmental attitude present during sharing-time also should prevail during the decision-making time. Most people will go along with the group if they have had their say. This is not to say you do not provide some structure. It is important to have regularly scheduled events to assure members you will be there for them. Each meeting should allow some time for mingling, and for a structured time. Professionals may be invited for periodic lectures because providing accurate and updated information is an important function of the group. A revolving door of professionals does not allow a group time to get acquainted or to develop a sense of belonging or ownership. The role of the professional as explained by one professional is to be on tap, not on top.

Support groups work for a cause and to increase public awareness. Some groups have developed directories; some have established clinics; some have coordinated an excellent conference such as this one; some have fought for accessibility rights; some have championed disability rights; and some groups meet only on the telephone. There are almost as many different kinds of support groups as there are support groups. Many leaders lament they cannot

get their group to do a big project - but remember, individuals will become involved on a larger scale when they've solved their own problems. Personal issues need to be resolved first, then individuals may want to address community issues. Support groups charge little or no money for the service and are constantly struggling financially to survive.

Many groups successfully collaborate with well-established organizations such as rehabilitation centers, seniors' centers, March of Dimes, Easter Seals, independent living centers, etc. To seek or not to seek help from local organizations is a dilemma for many support groups concerned about consumer control. If support groups work with local organizations, they must work out a collaboration that is mutually beneficial. The groups must lead and the organizations must follow. Total independence is the surest way to maintain control of your own group. Collaboration is often a realistic and sometimes necessary alternative but the group must maintain ownership and autonomy. Some of the most successful groups I know collaborate with many organizations. They don't ask a whole lot from one group, they get a little bit from a number of them. That does take some talent, but it does work and the group is still in control. Do not get hung up on raising money until you know what the money will be used for. Many groups find that donations from those who are helped can offset the costs of people who cannot or will not pay. In general, people like support groups because there is no bureaucracy.

In closing, I would like to explain our role at GINI, and how GINI and you can work together as leaders for mutual benefit. GINI is a catalyst. We organize the biennial international conferences which are a unique gathering of polio survivors, others with disabilities, physicians, rehabilitation specialists, and independent living advocates from around the world. By bringing all these people together, we share information, offer solutions to current problems, and plans to meet the challenges of the future. At these catalytic meetings excellent ideas are generated, poor ideas are dropped, and a spirit of camaradery is fostered among persons with disabilities throughout the world. I extend an invitation to all of you to come to our meetings. Your input is not only needed but is valued.

GINI started as a grass roots organization 30 years ago. We are committed to staying a grass roots organization. We publish - but we need your local support groups to distribute the information. We need the sharing and the caring health professional and polio survivors. We need you to contribute to our publications, and offer you a forum to share your successes and to ask your

questions. I believe we need to do more published sharing of ideas. Also, we can feature articles important to polio survivors, but we depend upon the local support groups to find the psychologist where the person can go or to be the listening ear at the other end of the phone or to find the podiatrists or to find the shoes. In St.Louis I know that's a problem, but definitely we need you to help do that part of the networking. As a publisher we can organize and publish the directory of clinics, health professionals and support groups, but we do depend on local groups to help compile the list.

GINI is a substantiator. Because of our 30-year documented history we can substantiate and collaborate with the problems polio survivors now experience. We can supply accurate and credible information to present to your physician, your insurance company, social security agencies, lawyer, and even your family members. We are a network of people. Person-to-person contact is very important; for instance: A Dr. Jones from India came to our fifth conference. He is a noted marine biologist and had polio when he was 53 years old. He is nearing 80. While recuperating in Southern India, he realized how horrendous the rehabilitation was. Dr. Fred Maynard of Michigan facilitated his attendance at our conference. Dr. Jones asked us to help him put on a conference in his home country. I got a letter from a gentleman from India, and he said he was doing some work with polio vaccinations there, also in Malta, and did I know anybody in either of those places. I replied that "there is a Dr.Jones in India wishing to have a conference set up. Maybe you can help him." He had a grant from "Save the Children Foundation" to go to India and thereby helped Dr. Jones with his conference. So that is how we helped.

Lastly, I would like to share with you the thoughts of a sociologist as to why support groups exist and why there is a dramatic increase in their numbers. The crucial issue seems to be one of: who is in control and who is making the decisions. There is a concern about the imbalance of any relationship, particularly in the provider/patient relationship. To regain this balance, all individuals engage in the demystification of the problem or of the disease; of the nature of the treatment and what care providers can give. This demystification empowers people to deal with the health care system.

**Rheta Davidson:**

Thanks, Joan, I think that's an inspiration to us all. The networking is so important and I think our identity is so important. We got lost in the shuffle for

about 30 years and now we know we're here and let's make sure the world knows we exist. Jeanette, would you please come up here?

**Jeanette Wilson, Pullman, Washington:**

You're beautiful people up here, too. Each of you has a special gift. You do have a faith that others don't even understand. You have a courage others envy. You have a stamina that hasn't even been recorded. Only post polio people know what it really means when they say it's difficult to walk, it's difficult to keep walking.

I have something I'd like to share with you as we leave. This is called "Foot Prints". Perhaps some have read it before and remember the beautiful picture of the beach and the footprints in the sand, and the words:

One night a man had a dream. He dreamed he was walking along the beach with his Lord. As he was walking, across the sky flashed scenes from his life. For each scene, he noticed there were two sets of footprints in the sand. One belonged to him, the other belonged to the Lord. When the last scene of his life flashed before him, he looked back at the footprints in the sand. He noticed that many times along the path of his life, there was only one set of footprints. He also noticed that it happened at the very lowest most difficult times in his life. This really bothered him and he questioned the Lord about it. Lord, you said that once I decided to follow you, you'd walk with me all the way, but I noticed during the most difficult times of my life there's only one set of footprints. I don't understand why, when I needed you most, you'd leave me. The Lord replied, my son, my precious child, I love you and I would never leave you. During the times of trial and suffering, when you see only one set of footprints - It was then that I carried you.

**Rheta Davidson:**

Thank you, Jeanette, for sharing it with us. This is how we all help one another. Joan brought up some things we discussed the other night:

1) With your support groups, with our support groups, what do you think are the important things - meetings..the telephone contacts..newsletters..all of the above or none of the above?

- 2) Information availability - about local knowledgeable, medical personnel and treatments.
- 3) Research - how can support groups help to raise awareness, lobby governments, raise funds for diagnostic and treatment centers.
- 4) What do you see as the most important role for a support group in your area?
- 5) What would your group like to see improved by organizations like GINI and PPASS?
- 6) Do you feel we are doing a good job and do you have recommendations for areas that could be improved?
- 7) Do you have any ideas on promotional aids for new style "March of Dimes" annual fundraiser and/or publicity promotion internationally?

**Sieglinde Stieda:**

I thought I'd start the questions off, because I did start a similar group in Quebec. I think that this organization is superior to anything I've seen anywhere - the way you've set up the small groups, the telephone networking, and the political action are three of the things I have found most helpful in its development. I find your political lobbying incredible.

**Jennie Beth McConnell:**

I bring you greetings from the States - particularly Washington State. I would like to say that I feel that we need to tap into the "March of Dimes" a little bit more. They have taken a lot of the funds, as you know, and used them for birth defects programs. I think it is high time they started helping us with the Polio Syndrome.

**Rheta Davidson:**

Yes, it is a fact that all the organizations that did raise money for Polio are now raising money but are using it for other types of disabilities. I don't know how we could get them to come back to raising money for us. It is certainly something we should all work on.

**Zosia Ettenberg:**

I've lived in Greater Vancouver for 4 years, but came from Ontario where the Ontario March of Dimes has now gone back to supporting post polio syndrome.

**Sieglinde Stieda:**

On the subject of the March of Dimes in Ontario and Quebec, since I am very aware of the situation in both provinces: When I first approached the March of Dimes in Quebec in 1985, I was told by their medical researcher "polio is not a problem in this province". After the Federal Government began making money available for research into polio, suddenly the March of Dimes took over 'Polio Quebec', the organization I had started. They ousted me.

A similar thing happened to a friend of mine in Ottawa who was instrumental in starting the Ottawa Post Polio Group. He too was ousted - in his case from OMOD. The main issues were that we wanted our organizations to be like the organization here, independent, for polios, by polios. We want to decide what the issues are. In both Quebec and Ontario the provincial March of Dimes organizations, when they learned Federal money was available, decided they would take over, would decide what issues were to be addressed, and I strongly objected to that. I am no longer a baby, or some mentally handicapped person needing others to tell me what I am to do. I am quite capable, and so are you!

**Eunice Staples:**

I discovered something recently that could be of interest to people belonging to other service clubs in your own community - get some of them involved with

you. The physiotherapist in the Edmonton clinic run by Dr. Feldman is paid by the Royal Canadian Legion. Perhaps it would help you.

**Rheta Davidson:**

The Royal Canadian Legion in Alberta has always been the province's March of Dimes and they have continuously kept funding the polio population in Alberta. I think that this situation varies from province to province. Perhaps at this point in time, I'd like to say I think this is why we need to stay independent provincially, because our Health Care system is administered provincially, not federally.

**Lavonne Schoenman:**

I'd like to respond to some of the people who feel left out because they're not getting funding or because they're not sufficiently supported. I'm from Seattle, Washington, and I'm involved with the newsletter there. For some reason I don't understand, in our big city we seldom get more than 3 or 4 people to attend a meeting. In the small outlying towns we get incredible support from the community and a lot of the people show up. We don't get funding for it. We're non-profit. We barely make ends meet and sometimes we are in the red. But it seems to serve a purpose, and I hear from people in Canada, from people in Mexico, and from people all over the US.

I'd like to encourage people to go home thinking that it doesn't matter who's funding you or is not, nor does it matter what you're able to do or what kind of physical shape you are in, you can do something. Maybe you are a listening ear to someone; a contributor to a newsletter; a fund-raiser. Whatever you are, I think we should all realize that we really have important qualities. We can use those and we needn't compare ourselves to others. We don't need to feel badly in Seattle because we don't have the kind of organization they do in California.

**Rheta Davidson:**

I felt everybody should know all about GINI because I knew about it. The USA newspaper, the "Globe", in February 1988, published a little bit of information about Post Polio and put in it our PPASS address. We don't know how they

got it. But we received more than 500 letters from the States and Canada, and we even got a letter from a person in St.Louis, Missouri, who didn't know there was anything that existed in the US. So there are a lot of people out there who haven't yet heard that there are support groups and people they can turn to. I think it's up to us to keep promoting this awareness so nobody is left alone anywhere, that they all learn they can turn to somebody who is in their own community, even if it's just somebody to talk to. We must not ever make the mistake of attempting to give medical advice. We can only give medical direction.

**Cathy Browne:**

I'd like to tell you what's been going on in our Nanaimo Group. Our meeting attendance fluctuates between 10 up to 40 people. Recently we find we've become a referral service, as well, because some calls we receive are not from polio survivors but they are investigating whether post polio is causing their own problems and being referred to us to explore the idea. We may start a referral list because it's easy, if you see a visible disability, to blame anything unpleasant on that. Members meet in a shopping mall for coffee. Our phone is often busy with members who want someone to talk to for a few minutes or to get someone through a rough spot.

**Lillian Dunbar:**

Has anyone here approached the Rotarians? They have mounted a worldwide fight against polio in the 3rd World Countries and they're very familiar with polio and what it's all about. My boss belongs to this group. He wanted my assistance to help them and I said "No, not unless you're prepared to help us here at home first." So far I've had no real response, but the Rotary Club is very active and knowledgeable and we should be pushing them to assist at a local level.

**Rheta Davidson:**

We have approached them. That was awhile back. I am having a meeting this afternoon with a Rotarian, so we'll see where we go from there. We use the

philosophy that people have said no to us so many times that it doesn't matter any more. We will just keep on going back until they say yes.

**Sieglinde Stieda:**

I live in the Fraser Valley. When I started "Polio Quebec" in Montreal 4 years ago, I did have \$300 seed money from the Montreal Rotary. I have not had that kind of success in Maple Ridge, yet. So I've had mixed successes.

**Betty Flock:**

I'd like to say that there are many Rotary Clubs in Calgary - Southwest, Northwest, etc., many groups. We had some friends in a couple of groups and we approached clubs separately, rather than under the umbrella of the head office of Rotary. What they wanted to do was give something specific, so we had one group give us a photocopier. They didn't want to supply funds. Also, whether this is applicable in other provinces or the States, I don't know but we in Alberta have been given a personal Post Polio Syndrome card with a number on it. The Alberta government allows us \$200 worth of therapy per year now. We're very fortunate, there.

**Rheta Davidson:**

That is another thing we're working on here, trying to convince our government that this type of treatment is very necessary for us and they should be providing it to us.

**Elaine Stoner:**

I'm from Vancouver, Washington, and I'm active in the Portland, Oregon, support group. I would be interested if those of you who have been successful in fund raising, will tell me what you are using your funds for. We just received \$5,000 from Safeway for our group. We're under the auspices of Easter Seal which has been very supportive and has allowed us some autonomy. The first thing we did was to hire a part-time office person to help with the newsletter and mailing lists. We are also organizing fundraising and going

through the process of becoming a non-profit organization and filing tax exempt forms and that sort of thing. Is that what everyone else is doing?

**Rheta Davidson:**

That's a really important point because I don't think you can go out and raise funds just for the sake of raising funds. You really have to have a purpose. At the Plenary session our Honourary President, Dr. Howard Petch, mentioned the need for polio clinics. I think this is something we'd like to get behind and see developed here in B.C.

**Cathy Browne:**

When we were invited to be delegates at this conference, we tried to find other ways to bring other members, and wrote to all service clubs in Nanaimo, spoke at one meeting and explained what the conference was about. The Kinettes were the only ones that asked us to come and speak. The Rotarians wrote and said their budget was already committed but to approach them again. Verbal responses from the groups was good, "We can't help this time but ask again." So it seemed to be a good way of doing it.

**Rheta Davidson:**

That's the first step in awareness, they know you exist.

**Cathy Browne:**

To the lady who got money from Safeway, they donate coffee and cookies for our meetings, they're very good.

**Shelagh Horel:**

What I'd like to say to everybody is many hands make light work. Try and divide the activities among the members.

**Lois Sayers:**

I'm from Kelowna and of course I can't keep my mouth shut when you start talking about money. I know we all need money and we have some people in our group who are looking at having \$20,000 some day. I think a good idea would be to set up our budget, our needs would not be great, and any money made over that could be used to pay our way to more conventions like this.

**Joe Kaufert:**

Just two quick observations of points Joan made and observations of the development of networks across Canada. I meant what I said about the four stars that I think you've achieved organizationally. I would like to comment on two issues that have been raised here, one with experiences both in Ontario and Quebec of the relationship with more professionalized groups such as the March of Dimes. A somewhat parallel experience in Manitoba is the dilemma of losing some of the consumer control and autonomy you have. This is true also in linkages with researchers and clinicians. You maintain that control and empowerment that you showed in this conference. At other conferences not organized directly by the consumers/polio survivors, you do not get the kind of sharing that's going on here and goes on at the GINI meetings where people that come with unique forms of expertise, come with an eye to sharing it.

In Winnipeg, the experience of my friends in the independent living movement with the Post Polio group, has been some reluctance to go back and approach service organizations in the same way we did in the 50's, they wanted a new relationship. I think that should be central when you think about approaching the March of Dimes or a service organization; to recognize that the older traditional model which centered on the disabled person rather than the broader rights issues, have really changed in the 30 years since they provided basic supports.

Interesting things have happened in Manitoba, our old March of Dimes had relatively little representation of consumers among the professionals and the management group. Three and a half years ago it was taken over by a group largely led by post polios who said "Look, we don't want the old March of Dimes model. We want a consumer-directed model." I think those things are important. When you think about approaching professionals and service

organizations, you've got to consider the power and autonomy you have and the fact that if you give that even to researchers who are willing to work with you clinically or in a research context, they need you as much as you need them.

**Rheta Davidson:**

Before I turn the microphone back to Joan for her summation, I would like to ask you the questions we started with. In the support groups and in our Society, what do you feel is most important or do you feel all three are equally important. Meetings? Telephone contact? Newsletters? Well, I guess it's unanimous that, although all three are important, the newsletter is clearly seen as the most important.

I'd like to take this opportunity to thank each and every one of you. I've never known such wonderful people. I pick up the phone and ask "Will you?" and you say "Yes!". You're fantastic.

**Russ Browne:**

When is the next conference?

**Rheta Davidson:**

You raise the money, we'll put on the conference. If we do it on the same pattern as GINI, it's every two years.

**Al Rourke:**

Would you like it in cash or a cheque right now?

**Joan Headley:**

I don't have any summation. I just wanted to respond to two things. About the Rotarians and the March of Dimes, I think most of the issues were answered. I talk routinely to the gentleman in Chicago who's in charge of the foundation

and he always says that the Charter prohibits them from giving aid to anyone but Third World countries, but he also says he does not have control over the individual clubs and so, again, the key is who you get to. Don't go all the way to the top, go to the individual groups; that is the key. The other thing that Rotarians are concerned about, they did raise millions of dollars for polio vaccine and as an organization they want to go on to something else.

If we talk to the March of Dimes in New York and you ask, "How do you help polio survivors?" they'll probably tell you "by about a quarter of a million or more dollars a year". That's based on the fact they have continued their commitment to polio survivors on ventilators. They've stopped buying braces, etc., but they are not going to say "Too bad, we are not going to help you pay for your ventilator any more, so you're not going to be able to breathe". So they still do that. You kind of play a game with them. If you just get them to give you a dollar amount, they can give some pretty large numbers, but they're not actually helping polio survivors, as we think of ourselves. However, they have maintained a commitment to the ventilator user; and we do talk to them frequently.

A lot of people do come to the GINI conference who have their way paid by various agencies and groups. If you use them all, I think that's beneficial. I'm totally impressed with your organization. It really is good and it has many hands. I'm glad to be here.

**Rheta Davidson:**

Thank you. We now declare the conference officially over and hopefully we'll all be together again in two years.