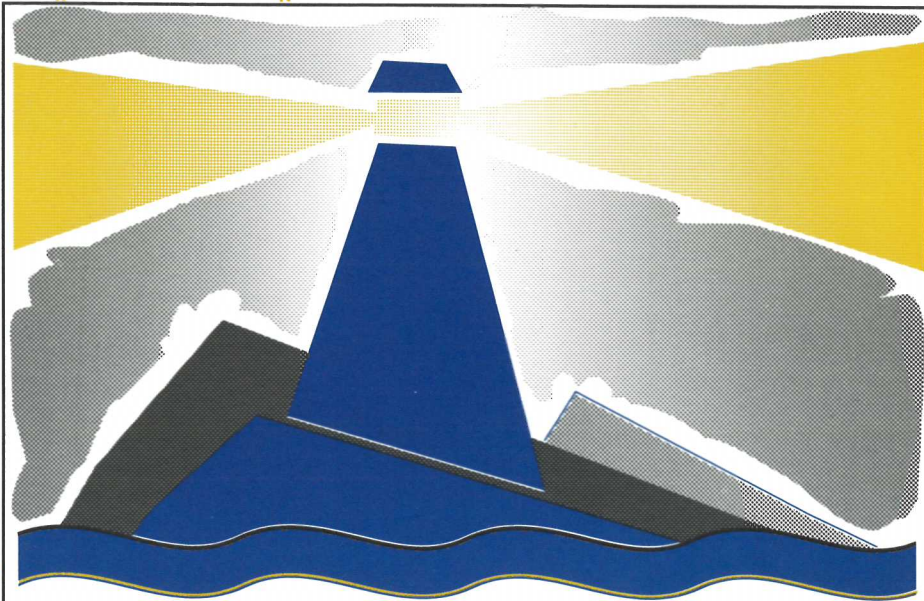
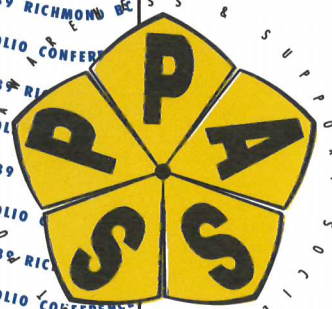


MANAGING POST POLIO PROBLEMS



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G.W. BRAUER EDITOR

Managing Post Polio Problems

**Proceedings of the
First Pacific Northwest Regional Polio Conference,
November 2 - 5, 1989,
Richmond, B.C.**

Edited by G. W. BRAUER

Conference sponsored by
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of British Columbia**

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Editor's Preface

The First Pacific Northwest Regional Polio Conference was held November 2-5, 1989, in Richmond, B.C. As an important event on the international calendar of meetings on Post Polio Syndrome (PPS), the Conference marked the coming of age of the Post Polio Awareness and Support Society of British Columbia (PPASS). PPASS is an organization founded in 1986 by Rheta Davidson, to increase awareness and information about PPS for the benefit of patients, health care professionals, and researchers.

The Conference was a resounding success and will surely have a significant impact on the level of awareness in the community, that polio, the scourge of the 40s and 50s, is again making life difficult for many of those who survived it the first time. These Proceedings are intended to assist in this effort by making a record of the Conference presentations and discussions more widely available.

While it was intended to render these Conference presentations essentially as they were originally delivered, it should be noted that all sessions were taped, and consequently these Proceedings are the result of converting informal and conversational material into a coherent and readable form. The extensive editing which was necessary will undoubtedly have resulted in some errors. Such errors are entirely the fault of the editor; where they occur, I hope that they do not impair the value of the affected material.

I herewith gratefully acknowledge the very helpful job of pre-editing done by Rheta and Warren Davidson, Diane Scaletta, Kathy Kess, Win Nelson, and Aline Redlich.

G. W. Brauer, Editor

Victoria, B.C.
August 31, 1990

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I. OPENING PLENARY SESSION

I. OPENING PLENARY SESSION

Walt Slocomb (Moderator):

Welcome to the first Pacific Northwest Regional Polio Conference on "**Managing Post Polio Problems**".

Because of the tremendous importance of volunteers to our organization, and especially to efforts like this very important conference, I would like, before we begin, to share with you a definition of **volunteers**:

"Hearts" to Volunteers

Volunteers are like FORD ...
... They have better ideas.

Volunteers are like COKE ...
... They're the real thing.

Volunteers are like PAN AM ...
... They make the going great.

Volunteers are like PEPSI ...
... They've got a lot to give.

Volunteers are like V-05 HAIR SPRAY ...
... Their goodness holds in all kinds of weather.

Volunteers are like HALLMARK CARDS ...
... They care enough to send the very best.

And most of all,
Volunteers are like FROSTED FLAKES ...
... They're GRRREAT!

To open the conference, it is my great pleasure to introduce Dr. Howard Petch, President and Vice-Chancellor of the University of Victoria,

as well as the Honorary President of the Post-Polio Awareness and Support Society of British Columbia. Dr. Petch will be retiring at the end of this academic year in June, 1990, and will become more active in PPASS at that time. Would you please welcome Dr. Petch.

Dr. Howard Petch:

Thank you. It is a great pleasure to welcome you to the first Northwest Regional Conference of PPASS. It is a privilege, not only to serve as Honorary Chairman of this Society, but also to be invited to open this Conference. I arrived a little late last night so I missed most of the reception, although I did get in for a few minutes and managed to meet a few of you.

I never interacted very much with others who have suffered from polio. The fact that in our university, with its 13,000 students, almost 2,000 full time and another 2,000 part time employees, there is to my knowledge only one other person that suffered from polio, has resulted in my having had very little interaction over the years with other polio victims. So it was very interesting for me to find, within minutes of conversation, that we all have so very much in common.

Just to give some examples, the questioning now of whether we really had polio or not, and the difficulty of getting past records which, in my own case, are more that 60 years old now. It's no wonder that it is very difficult to get these records but sometimes they are necessary to back up medical claims and so on.

The lack of knowing, at least in my own case, of where to get help; the frustration of being referred to orthopaedic specialists, time after time, who cannot really help; the difficulty of getting referrals to what I call complementary health professionals, who in some cases can offer real support and help to us. These are just some of the many frustrations that I think this Society can help alleviate. Especially by networking, letting us inform each other about available supports, and overcoming the difficulties and lack of information about where to go for help.

Of course, these are among the main aims of the Society: first of all to increase awareness, awareness among the medical professions, awareness among the governments, and awareness in the general public. And I think, in my case for

example, that maybe even awareness among ourselves that we have so much to offer each other.

I think this matter of awareness really has two levels. Nowadays one hears a great deal more about post-polio syndrome, and certainly we need to raise awareness of it, but I think, very important as well, are the degenerative problems associated with aging. These attack everyone, of course, but they are accelerated in the case of people who have been victims of polio, not only accelerated but they are compounded, and one can have problems in strange places. The weakness causes imbalance in our body and so, with a shorter leg for example, one can have spinal problems, or the strong side begins to break down from excessive use.

So in developing this awareness, I think we need to work on both of these levels. That is, the degenerative problems associated with aging but which are compounded in the case of polio victims, as well as the post-polio syndrome itself. We also have as a main aim the giving of support as I mentioned before, and forming these support networks. I think we need to look to the future as well, and encourage more research and emphasis in earlier diagnosis of these post-polio problems and, hopefully, more effective treatment.

I would hope that here in British Columbia we might work toward establishing a post-polio clinic. In my view this is certainly needed.

Just before officially opening the conference, I have the pleasant duty, on behalf of the Board of Directors and all members, to give our heartfelt thanks to Rheta Davidson who is our founder and the President of PPASS. She founded this Society in the spring of 1986 in a small way in Victoria. There are now over 2,000 members in many countries. This absolutely phenomenal growth is largely due to Rheta's vision, energy and dedication. In this she can serve as an inspiration to all of us. I would like to ask Rheta to come forward to receive flowers, please.

And Warren, would you come up as well? Warren has provided great support to Rheta, I don't think she could have done the job as fully without that kind of support. We men are used to getting support during all of our working days, and this is a wonderful example of reciprocal help by the husband.

I now declare this Conference officially opened.

Walt Slocomb:

Thank you very much, Dr. Petch. This morning you will be hearing from the six panelists. There will be a workshop this afternoon with the same six people involved and they will take questions at that time.

I would now like to introduce Dr. Joseph Kaufert. He received an M.A. and Ph.D. at Northwestern University, and has been on the faculty of St. Thomas Medical School of London and the University of Texas. He is a Professor in the Department of Community Health Sciences at the University of Manitoba and, as a social scientist, is currently engaged in research on 'aging with a disability' and 'impact of life support technologies on people with post-polio impairment'.

Dr. Joseph Kaufert:

It is a great pleasure to be here. I have followed the activities and development of your group over the last three years via your newsletter and informal contacts. As somebody who had a minor episode of polio in the '52 epidemic, I became very interested in post-polio support groups as an insider.

This morning I would like to deal with two themes: the pattern of a disease and what implications that has for our coping with it. I will deal with these not as a clinician but as somebody who is interested in what we can learn from the history of our early experience with polio and with medicine's early experience with the epidemiology of polio. My own work has involved a large sample of all the registered cases of polio in Manitoba from the epidemics of the 1950's. So it was fascinating for me to come here and talk to people like Shelagh, who had actually been a nurse on the wards that I am working on today, with some of the same people that had survived and lived in hospitals over the ensuing 35 years.

The problem with being a guest expert was illustrated by Will Rogers who came as a guest expert during World War II. He was touring the Allied naval bases when the U-boats were taking their toll of Allied shipping. And they asked him, "As an outsider, Mr. Rogers, what would you do with the U-boats?" And he said, "Well, if you were to heat up the North Atlantic by 5 degrees the U-

boats would have to come to the surface because of the expanded air volume within them, then you could pick them off on the surface." And they said, "That's a nice concept, Mr. Rogers, but what about practicality?" To which he replied, "That's your problem. I only deal in concepts."

That is sometimes the problem of the guest expert, whether he be your individual physician or a person like myself, who is interested in the group activities of people, both during the epidemics and today, in terms of self-help initiatives and your relationships with medicine.

Let me spend about seven minutes on some historical elements of the polio experience, all of which I think have a parallel for what people are doing today. This picture shows one of the teaching wards at the Winnipeg Municipal Hospital. The interesting thing is, not only have these people survived but so have the networks they actually lived in. And this is our survivors group picnic on the lawn of the same hospital just a couple of summers ago. So there is a personal history as well as a history of the epidemics.

The other side of the acute care experience of polio was one of incredible mobilization, both from the standpoint of the consumers and from the standpoint of the people who were involved professionally. This slide shows one of the two wards in the Winnipeg Municipal Hospital; each ward had 50 iron lungs. The really important element of this slide was that a whole generation of physicians in Winnipeg were involved with the acute stage of polio.

Ten years ago, when we began to become involved with the late effects of polio, we had very few physicians left who remembered the acute and rehab phase. We had to develop interest, expertise and knowledge in a new generation of physicians. That was very difficult to do because, as your report indicates in the quotes in the B.C. and West Coast survey, "this apparent lack of interest in an 'old disease' was one that meant you had to reconnect". You had to find some of the physicians who knew the acute effects and form new relationships with them.

The other thing was the whole idea of public information and public mobilization. What we are faced with today as consumers and as health professionals is a need to influence the policy process, in terms of things like home care benefits or the availability of respirators, etc. This poster is about 1949 vintage and shows the power of organizations like the March of Dimes, in

getting massive public support behind something which subsequently became a public crusade.

The dilemma that PPASS, and the organization that I am part of in Manitoba, faces today is how we create public awareness and mobilization and how we generate the kinds of resources they generated during the epidemics. The basic work and research done by the Salk and Sabin teams was supported by at least 10 million dollars, about the equivalent of 140 million dollars of current research money, which was used to address the problem.

Today the networks are thinner, the public awareness is thinner, and the potential for mobilization is different. This picture (I happened to be at one of the Warm Springs Conferences assembling medical professionals) of Roosevelt in the Little Whitehouse, which was unfinished at the time he died of a stroke, was very significant. To me, it symbolizes the role of leaders in the early (acute care) mobilization of people to fight polio. But it also emphasizes the need to look for a new generation of spokespeople, something you have already done very effectively in B.C. As you can see in the people that have just been introduced on the podium, you have important potential linkages in university and policy circles.

Many of you have been advocates in many spheres, so you may find some of the new leaders will be in their sixties, seventies, and eighties. This whole era of late polio effects, of re-mobilizing our leadership is a very significant issue. It has been very significant in the history of the 'independent living' movement in Canada. I am a member of three advocacy groups for the disabled in Winnipeg. Disabled Peoples International has been headed by people like Jim Dirksen who has late polio effects. The head of our Independent Living Centre, Allan Simpson, and his wife are polio survivors. So it isn't enough to rely on our polio-related networks, we have to exercise the power we have as members of the broader consumer perspective (health consumerism, rehab consumerism, etc.) in looking for policy alternatives.

This is an old poster from about 1953 and the only thing to learn from it is that just before the Salk and Sabin vaccines became available we didn't know much about the disease process. We weren't sure how to prevent it. We had lots of images of not getting chilled, not getting tired, avoiding public situations. The lesson to take from this aspect of the history of polio is really that today we are again dealing with areas of medical and epidemiological ambiguity, again we're not very sure about things.

There are many such gray areas. Even as medical science has progressed in the last eight years by finding that there is not a residual viral threat, today we are dealing with a chronic illness, largely using a traditional inventory of medical, rehab and consumer skills. As there was uncertainty during the '52 and '53 epidemics, we face a similar uncertainty today, and it is important for us to recognize that we may have to act before all of the medical answers are in. That action may have to come from the consumer side as well as from the medical side.

The main thing I'm interested in here is the idea that the vaccines provided a public solution. The recognition that we had 200,000 to 350,000 people as the residual population is not something emphasized in medical school curricula. Three days ago I was talking to first year medical students about epidemics and how they affect people. I talked about the current AIDS epidemic and I showed a few of the same slides of the epidemics that you are so familiar with. It was a problem of getting them as future practitioners, to understand the idea of risk, the idea of communities coming together and mobilizing to deal with a general public health threat, mobilizing again to deal with the rehabilitation and community living problems, and finally to understand the mobilization that you are doing today as consumers. Only with such understanding will we, as providers, be able to respond effectively, today and tomorrow, to the problems brought to us by the sufferers of the late effects of polio.

This slide represents a curve which shows the dramatic effect of the Salk vaccine. These are the mortalities. The jagged line shows the cases and notifications of deaths related to polio which probably killed only about 4% of the people who were documented cases. This dotted line that goes up is really the impact of the Salk vaccine first and then the Sabin vaccine, so you have a dramatic public health intervention that ended the epidemics. It wasn't even very expensive once we had the vaccines.

The kind of "quick fix" represented by the vaccines is, as you all know, unlikely to occur with regard to the late effects of polio. The other points that I would make have to do with the history of technology and it is something that you are very familiar with. Very often you're more familiar than the doctors who prescribe better respirators or better orthotic devices because you are the real experts in the technology you use.

I've been part of an independent living centre that received a small amount of money from the Rick Hansen Fund, to look at one area of technology, respirators, as used in Canada. They found incredible variability between the technology available in Manitoba versus the innovations available in Vancouver. Independent living units varied between what is available in Ontario (which even varied depending on what area of Ontario was involved) versus what's available in the Maritimes. It is important to recognize that medicine often evaluates new technology according to the maxim that "newer is better". This slide shows tank respirators, iron lungs and the first generation of rocking beds, all circa 1952-53. Rocking beds seem like old technology to young medical students yet they are familiar, workable technology that has functioned for 25 or 30 years.

I think the important things in terms of 'late effects' is for professionals to listen to you about what you have used throughout your own life. There are two forms of expertise, 1) we've got to get Medicine involved and tap the new expertise that Medicine has and 2) you as experts in terms of the conditions that you bring.

If we understand the history of technological change and listen to what consumers are saying, there is often a trade off between facilitating what we do and the limits that technology places on us. The only way we, as health care providers, can deal with that is to not always listen to the experts about what the next generation of technology offers but to listen to you as well. When my friends in Manitoba received the latest LP6 generation of positive pressure respirator they found the 40-below winters affected the micro chips. It affected the programming! It was very important to listen to the consumers' expertise.

Policies that were developed in Manitoba in 1955 at the time of the epidemics were the First Post-Polio Respiratory Home Care Programme, as well as other programmes that preceded Medicare and Medicaid in Canada, and we actually had about a third of the acute respiratory cases going home with an innovative programme that was very cost effective. It cost the province less than \$1,300 a year because helpers from the family were involved, and equipment was provided in the home. Therefore we need to look at the history of programmes that have supported us in the community and we need to recognize that our perspective as consumers may be different than that of physicians or administrators.

Things like ventilation technology vary a lot in terms of what you can get in Vancouver, in Winnipeg or in Toronto and what is paid for by the different health plans. The levels of government funding are very different and the levels of public consciousness are very different.

Another focus has to do with the consumer movement, the need to understand the history of consumerism. A lot of the people involved in our national obstacle report were those people of your generation who became involved in broader consumer advocacy and human rights legislation. The fact that disability concerns are enshrined in our Charter of Rights is the result of a very strong involvement in these debates, and is attributable largely to the effect of people who became involved in human rights legislation.

In the history of consumer movements, developments like PPASS in B.C. are relatively recent; but you have people like Joan Headley, who is continuing the legacy of Gini Laurie, the creator of polio networks across North America. The history of these networks shows that what they did after the epidemics, what they did as we were forgetting about the special needs of people with polio, and what they are doing today in terms of coping with late effects, is very important.

With regard to the pattern and epidemiology of polio, we in Manitoba were lucky enough to have lists of everyone diagnosed with a confirmed case of respiratory paralytic polio, as well as most of the non-respiratory cases. So when we started out in the 80's to look at all of the surviving cases of polio in Manitoba, we were in a different situation than you were in B.C. Your study dealt with the present population of British Columbia, and a large percentage of those had had acute polio in many other parts of the world, so you did not have access to a list similar to that of the Manitoba study.

In order to understand the epidemiology of the late effects of polio we've got to look at a wider sort of a pyramid. In Manitoba it is really a pyramid of all 15,000 people hospitalized during the main epidemics. By doing that we attempted to find everyone. We found 90% of the people who had respiratory polio and we received information from about 70% of the people that had paralytic effects and about 60% of the people who were hospitalized with non-paralytic polio. The main point I would make is that as consumers, when you follow up a population, you want to try to find out what happened to everyone. It's more powerful for consumer lobbying. As an epidemiologist, I would say it is important to try to understand the group of people whom the late effects

network has not yet reached and who don't identify themselves yet with parts of the consumer movement. They may have exactly the same issues in terms of both disability and their relationships with health care providers as everyone else.

I apologize to you for dealing, like Will Rogers, only in concepts, but I think it might be useful to start the conference with a few of those reminiscences, because you do have some expertise related to your own memory of the acute effects, as well as the fact that you have lived with that condition for 30 or 40 years.

Walt Slocomb:

I would like at this time to introduce Dr. Neil Cashman. Dr. Cashman was born in Weymouth, MA, and received his medical training at the University of Massachusetts. His neurological training was at the University of Chicago Hospital and Clinic. One of Dr. Cashman's appointments was Director of the Post-Polio Clinic, University of Chicago, in 1985-86.

He is currently a neurologist and researcher at the Montreal Neurological Institute and also runs the Post-Polio Clinic there. Dr. Cashman has had many articles and books published including several related to post-polio syndrome. He participated in The Third International Conference on Polio and Independent Living, in St. Louis, MO, in 1988.

Dr. Neil Cashman:

I want to thank PPASS for inviting me and also my wife for letting me come; with three small children in the house it is not an easy proposition. Joe Kaufert's eloquent and compassionate talk is a hard act to follow but I'll try.

Polio as a disease was described a little more than one hundred years ago, although there are Egyptian hieroglyphs that suggest polio is a very ancient disease. Except for a few cases per year, acute polio was essentially eliminated, in North America, in the '50's and '60's. What is not on this time line is the first case of post-polio syndrome which I believe was described by Charcot, a French neurologist and the father of Neurology. That was back in 1875. Since that time there have been a handful of cases described in the literature, and in

the late 1970's-'80's suddenly post-polio syndrome took off. There was much more public awareness and, consequently, much more medical literature regarding this syndrome.

This slide is to review for you the sites of attack of the polio virus. The big thing up in the left-hand corner is a section of a spinal cord. You can see the black section in the front is the anterior horn of the spinal cord, or anterior horns. That's where the motor nerve cells reside, the ones that send their processes to the muscle and make the muscles work. That, of course, is the place where the polio virus strikes. Motor nerve cells in the brain stem are also affected. There are other places in the nervous system that are affected by the polio virus, and this makes me wonder if there isn't more than one post-polio syndrome.

Today we will concentrate on the motor syndrome. This just shows the few people who actually contracted paralytic poliomyelitis. Something like 95% of people who had a viral infection had what is called an "unapparent infection". They didn't know they had anything. Another small percentage had a flu'-like syndrome that passed with no residual and maybe 1% to 2% developed involvement of the nervous system, usually a meningitis, sometimes a paralysis or a death of motor cells resulting in paralysis.

This slide shows the dramatic decline in new cases with the introduction of vaccines in the mid-'50s. You can see, in the first part of this century, polio was what I call the "endemic epidemic". It happened every summer, but the number of cases was fairly low. In the 1940's-'50's, with the improvement in hygiene in the USA and North America in general, there were people affected by the polio virus for the first time at an older age and who thus had a more serious illness. There were hundreds of thousands of people affected during this period. Polio started to decline with the introduction of effective vaccines.

However, despite the fact that acute poliomyelitis is for all intents and purposes eliminated from North America, there were something on the order of 200,000 to 300,000 people in the United States and in Canada 30,000 - I'm not sure - who have had paralytic poliomyelitis and have some residual effects from it. That makes it the second most common cause of paralysis in North America, which came as a surprise to me many years ago when I read this figure. So, while the vaccines for all intents and purposes eliminated acute poliomyelitis, all is not fine.

In addition to residuals there were people from this large group of the '40's and '50's who were starting to report new symptoms decades after their poliomyelitis. This shows a list of symptoms which comes from a landmark article by Mary Codd of the Mayo Clinic, detailing an almost bewildering array of new complaints which people in Olmstead County where the Mayo Clinic is located, were reporting. Although it is hard to make sense of some of these complaints most of the major complaints appear to revolve around three major symptoms - that of new weakness, pain and fatigue.

Another trail blazer, Lauro Halstead, surveyed a population in Texas and again found a large percentage of people reporting new fatigue, weakness and pain. Our preliminary data at the University of Chicago in 1984-85 when we first started seeing post-polio patients show these three new symptoms figuring prominently in the new complaints of polio patients. This has also been borne out in the post-polio clinic in Montreal.

Our knowledge about some of the risk factors for developing the post-polio syndrome come from an early study by Lauro Halstead. If somebody was hospitalized at onset, if they were over the age of 10, if they required a ventilator and if all four limbs were paralyzed when they had polio, they were at high risk for the ultimate development of new symptoms. As sex plays very little role in this, i.e. there is no significant difference between women and men with regard to developing post-polio syndrome, it is used as a kind of control variable.

At first glance, the age of onset doesn't seem to correlate with the rest of the factors which are severity factors, but in fact, when you had polio over the age of 10 you were more likely to have severe polio, so that fits in perfectly with the other risk factors.

What causes the post-polio syndrome? This is a table from a review that Burk Jubelt and I wrote in Chicago, trying to list all the mechanisms that have been proposed for the post-polio syndrome. Chronic polio virus is the thing everyone thinks about first. Is it possible that this virus has survived in latent form in the nervous system for 20 or 30 years? The most recent immunologic and molecular biologic data would say that the polio virus does **not** persist in the nervous systems of those who had polio.

Another, more compelling, theory is that the natural death of motor neurons that occurs with aging, when superimposed upon the static damage of polio,

results in an accelerated new weakness. However, the normal loss of motor neurons with aging occurs, or at least becomes prominent, after about the age of sixty, when we, in fact, have seen people in their thirties who have the post-polio syndrome. It appears the greatest risk factor is the length of time after onset of polio, which has a mean of about 35 years, rather than the age of the person who has the post-polio syndrome. Thus, a theory like this invoking death of motor nerve cells with aging doesn't really fit in very well. It doesn't correlate with the age, it correlates with the length of time after onset of polio.

What I believe is the most compelling theory was originally proposed by Dave Weickers in an article in the Medical Journal **Muscle and Nerve** back in 1982 and I believe this article to be prescient in its understanding of the post-polio syndrome. It is illustrated by a cartoon from an article by Marinos Dalakas, another worker in the post-polio field. On top is a normal motor unit and we neurologists and other physicians talk about the motor unit as a motor nerve and all of the muscle fibres it enervates - it is kind of like a tree. The motor nerve cell, the motor neuron, sends an axon to all its branches. This makes the tree much larger than it was originally designed, i.e. there are too many branches on the tree, and the motor nerve cell now supports seven or eight times as many muscle fibres as it was designed to support. These extra branches are not indefinitely stable. They start to be lost. They start to degenerate with the passage of time, then twenty or thirty years later enough branches are lost to produce new weakness.

You'd think that, if this was the case, it should be a relatively easy matter to diagnose the post-polio syndrome. We had a number of clinical criteria, a number of historical statements that correlate with people having this new syndrome, but there was no objective diagnostic test that neurologists, physiatrists, other doctors could point to and say "Yes, the post-polio titers are high with this case of post-polio syndrome."

We started looking at this problem in 1984 and this is a list of studies that have been performed in post-polio syndrome, suggesting that we can diagnose post-polio syndrome by changes in electromyography or muscle biopsy. What we did was go back to a classical paradigm of investigation, to compare people having what we call post-polio syndrome or at least having the new weakness part of the post-polio syndrome, and compare them in every way to people who were not having post-polio syndrome, people who had polio but were stable with no new complaints. We had thirteen people suffering from bad post-polio syndrome and five controls, the people who had had polio, but had no new

symptoms. On all the factors that we could match, age, time after polio, severity of the original polio, the two groups were equal.

We studied them with conventional electromyography, EMG. We also used a research technique called Single Fibre EMG. Single Fibre is different in that it allows us to quantify the degree of old polio and the degree of ongoing denervation - the degree of ongoing loss of connection between motor nerve cells and the muscle. We also performed muscle biopsies in a muscle that was strong enough not to be affected by the biopsy and these are the different pictures of people whom we biopsied.

I'm not going to go over the details of what we look for, suffice it to say we could get a rough quantification of the severity of old polio and the severity of new denervation, new loss of connection of motor nerve cells. What we found was a surprise, such a surprise that it was accepted by the **New England Journal of Medicine** for publication. The surprise was, we did find evidence of ongoing denervation in people who were complaining of the post-polio syndrome. But we also found signs of denervation in people who were completely stable.

This is the muscle biopsy data, the gold standard for neurologists and neuropathologists to assess whether or not there is ongoing denervation. Again, while we found evidence of ongoing denervation in the people who were complaining of the new symptoms, we found identical changes in the people who were stable. What does this all mean? Well, from my point of view, it means that the indications for electromyography and muscle biopsy in post-polio syndrome are not good. In my opinion, there is no way you can make a diagnosis of post-polio syndrome from electro-myography.

There are certain things that have to be ruled out that **can** be tested by EMG: nerve pinching, a slipped disc, things like this, but if you are trying to make a diagnosis of post-polio syndrome, that is not possible. Hopefully, the use of this test has declined since that article. What we think, though, has come up in a recent series of tests using an entirely different technique called Macro EMG. Again I don't want to get too complicated, but what we do is assess the size of the tree. We are able to tell how many muscle fibres are enervated by one motor neuron.

In other words, the question is whether this motor neuron is able to support this hugely enlarged tree or not. This slide shows a control patient. You can see all

the little black points all the way up to nine. That means those motor units are markedly enlarged, despite the fact that this patient's muscle biopsy and other electromyographic tests show evidence of ongoing denervation. She has been able to support markedly enlarged motor units.

Here is a patient with the identical findings on conventional EMG who has a markedly different picture on Macro EMG. You can see that the size of the units is now way down toward the small end. In our opinion, what this means is that when you recover from polio you have a markedly enlarged axonal tree. With the passage of time, some of these extra branches are taken off, they degenerate. That is a natural process. When somebody passes through a threshold where the size of the motor unit is sufficiently small, then they start to report new weakness. We are trying to further develop this theory. This may ultimately become the diagnostic test for post-polio syndrome.

I must say that today you will hear how all of us 'feel the elephant'. Some people feel the trunk, some people feel the tail, some people feel the side. I'm a neurologist and this is, to me, a neurological problem. To a physiatrist it is a physiatric problem. There will be different perspectives and, hopefully, you will get some kind of feeling about the way we are all proceeding on this. But there are going to be holes in what I say and, hopefully, holes in what some of the other people are going to say.

Next I want to talk a little bit about polio, and a little bit about our research. Then I want to spend a few minutes talking about the other symptoms of the post-polio syndrome. Briefly, we have a list of things we think about when somebody comes in with pain. Interestingly enough, pain is the most common reason that people come to our clinic. But pain is probably the most treatable symptom of the post-polio syndrome. If you can make a diagnosis, there are treatments for every one of these possible syndromes.

Just starting at the top, there are people who report muscle pain and/or cramps on activity. The treatment for that is very simple. It is reduction of activity. Tendonitis and bursitis are very common among people who have post-polio syndrome. I liken this to having tennis elbow in every joint in your body. That also is treatable. Fibromyalgia is something that I've found over the last few years, although my physiatric colleagues have been telling me that it is there all along. These are just some of the points where tendonitis and bursitis can result. The supraspinatus tendon, up in the shoulder, is a commonly-affected

place, as is the pes tendon in the medial aspect of the knee, and the trochanter bursa.

This is the fibromyalgia syndrome from a recent review of this syndrome in the **Journal of the American Medical Association**. It is an aching syndrome in large muscles of the back and neck, the shoulders, the legs, and the low back. It is associated frequently with disturbed sleep and a variety of other non-specific symptoms - fatigue, a feeling of swelling, headaches, and perhaps the most important here is the problem with disturbed sleep. If that diagnosis can be made, muscle tenderness with trigger points on a physical exam in conjunction with disturbed sleep, there is a drug that works almost every time in my experience. This drug is "amitriptyline" or "elavil", used in low doses. Briefly, in large doses "elavil" is used as an anti-depressant. In low doses, it is used for neurological pain, migraine, and fibromyalgia. The dose that is used for depression is ten times the dosage we use in the post-polio clinic. And here it is used for a different reason: fatigue. We became interested in fatigue because it has many of the characteristics of another syndrome, one that few physicians other than neurologists ever see, myasthenia gravis.

Generalized fatigue is also associated with muscle fatiguability. That is a symptom by which you get increased muscle weakness on exertion that will resolve on rest. And this is something we can test for in the clinic. It is something we see in post-polio syndrome. It is something we see in malignant motor neuron diseases like amyotrophic lateral sclerosis and it is something we see in myasthenia gravis. It points us to the junction between the nerve and the muscle - the neuromuscular junction. It pointed us to research on drugs that can enhance communication between the nerve and the muscle.

To summarize: I have had to break up what I usually talk about into two sections. I've talked a little bit about acute polio, the symptoms of the post-polio syndrome, and the research approaches that we are using to try to get to the etiology of the syndrome. Thank you for your attention.

Walt Slocomb:

Our next guest is Dr. Alan Bass. Dr. Bass received his medical education at Durham University, in England. He is currently Clinical Director of Rehabilitation Medicine, Greater Victoria Hospital Society. He is also Adjunct Professor, Department of Psychology at the University of Victoria. His

primary focus has been Rehabilitation and Sports Medicine, and he has had several appointments as Medical Director at several major world sports events. He was an Olympic juror at the 1972 Olympics in Munich. Dr. Bass has participated in numerous symposia and has been involved in eleven publications. During the past twenty years he has been an invited lecturer at numerous conferences in Europe and North America.

Dr. Alan Bass:

I shall be brief, and I shall also be very careful, as I am in front of our founder, Rheta Davidson. Once you are found by Rheta you are truly "found". You never get lost again. No matter how many times you say "I don't think I'll be available" eventually you succumb when she says "You will be available, won't you?" I also see a fair number of my patients in front of me as well, so I will have to watch it.

Just before I came up here I met a patient who told me that she can now manage six lengths of a pool and walk half a block, neither of which she could manage a year ago. That may not sound like an awful lot to most people, I am sure that you, who are involved with post-polio, know just how important that kind of progress is, when you have struggled for so many years.

I may be one of the few people here, apart from people who actually suffered from polio, who remember the last great epidemic. I was in Europe at the time, in England, during the epidemics of the mid-fifties and I was in the services where large numbers of young people were smitten by paralytic polio.

Over the past couple of years, I have had 104 patients referred to me with problems which are clearly post-polio. They were referred from various physicians, and from various communities besides Victoria, including Cranbrook, Kamloops, Kelowna, Vancouver, Prince George, and Campbell River. I couldn't understand why they were coming these long distances to see me. Then I realized that there were a lot of physicians who were not happy about treating post-polio. First, because a lot of them didn't recognize it as a syndrome, and secondly, because when they did recognize it, they didn't know what the devil to do about it and they didn't know where to go.

When I spoke to the first few patients I realized that they were in exactly the same boat as the physicians. They didn't know where to go either, and

therefore it seemed to me we were fulfilling a reasonable service by saying:
"Yes, we will see post-polio patients and we will see if we can help."

I think doctors have a problem in that we tend not to like failure. When polio initially affected people, we couldn't stop it. Therefore somewhere, although it was thirty years ago, we feel we failed, and we don't like to have it paraded in front of us. So, generally speaking, we feel just a bit uncomfortable with the recent emergence of the sequelae of polio. For a similar reason perhaps we also tend to have a lack of awareness of what has happened in post polio over the last five, six, seven years since Halstead and Weickers had their symposium at Warm Springs. Much has happened in that period, of which a lot of physicians are unaware: there is a lack of awareness of what is available in the way of physician help, a lack of available knowledge of resources, and a lack of awareness of what is available in the form of treatment.

It was interesting to see Dr. Cashman's slides. In fact this is exactly our problem as well: the fatigue and the weakness in muscles that had previously been affected, the weakness in muscles that hadn't been affected before, the pain in the muscles, and pain in the joints. I also had a lot of people complain of sweating and difficulties in sleeping. I only had one, out of the 104, who complained of breathing problems. These were what I call clinical symptoms but, as a physiatrist, I have to say "now how does that affect you, and what you want to do, and the way you live?"

Of course, it is very important how many motor neurons are working and, in fact, this will tell us exactly how weak you are and what hope you have; but I also want to know "what does it stop you from doing?" And you might say "I don't find it as easy to hitch my bottom up and get my pants on." "I find it difficult to get my socks on." "My grip is so poor I can't get my buttons done up." "I can't walk as far." "I can't manage stairs." "I can't get in and out of a wheelchair." "I can't transfer from my bed to the wheelchair." etc. These were the **practical** points that my patients raised with me.

Now I asked everyone "Do you expect me to cure you?" They all smiled and said "Of course not, you idiot! We know there is no cure." I said "So what do you want of me?" (because I think that this is a valid question doctors are entitled to ask). And they said "We would like you to tell us why we are getting these symptoms and is there anything that can be done about them."

And to some of them I have had to say, "I am sorry. There is little I can do." I have never had anyone look very distressed. They may have looked sad, yes, but none of them have ever sounded resentful. None of them ever levelled a tirade against me or the medical profession. Some said, "Well, thank you, c'est la vie." and "That is fine and thank you very much for at least telling me what is the score."

Now, as far as the problems of post-polio were concerned, I found several cases of secondary arthritis. I notice that Neil Cashman's slide also drew attention to this, and secondary soft tissue, fibromyalgia, which is a muscle aching around joints, particularly around the shoulder, around the hips, around the big strap-like muscles of the back.

Why do we get these problems? Well, it is fairly easy to understand. If you have a weakness on one side, you tend to overuse the other side, and if you overuse this other side, it is not unreasonable to get pain in it. So, although it is not truly post-polio, it is caused by poliomyelitis. If you cannot walk on one leg, or if the muscles around the joint are weak, you will damage the joint and you will get arthritis in it. That is arthritis due to polio. If, on the other hand, you overuse the muscles (i.e. joint) on the other side, you may get secondary arthritis. That is **not** post-polio, but it **is** arthritis which might not have occurred had you not developed poliomyelitis earlier.

Some of the cases we found created a problem because I thought they were mainly due to aging. As you will recall, Dr. Cashman said that, at the age of 60, muscle power drops off, but you can always cope with about 50% of your motor units. True, you **can manage** with those; but if you only had 50% at the age of 59 and you lose **another 50%** by the age of 62, you will only have 25% of what you should have, and then you really **are** weak and struggling.

Obesity, about which I know a little, is always a problem. What you can carry around easily at 40, you carry around with more difficulty at 50, you have even more difficulty at 60; particularly in view of the fact that your motor units are decreasing. In addition, we found several other interesting problems that had nothing to do with polio but accounted for the aches and the pains and the problems. There was heart disease which hadn't been recognized before.

We had chest disease that either was de novo or had been advancing, and we found one or two cases of other neurological complaints. We found one other unrelated disease, a granulomatous disorder, which was causing the patient to

feel fatigued and generally ill and giving them generalized problems. We also found primary connective tissue disease. Lupus and rheumatoid arthritis of late development which was assumed - because of the weakness, swelling, and pain - to be post-polio.

These are all very difficult. Post-polio syndrome is not an easy diagnosis to make. Although I feel reasonably comfortable now, having been dabbling in it for a long time, I will not make a diagnosis of post-polio if I am in doubt - not without neurological confirmation. Since my background is rheumatology initially, I am a non-electromyographic physiatrist, if you like. I ask Dr. Simpson to look at the patient and say, "Does this patient have post-polio?" Now he sees the ones I think **have** post-polio. The ones I am pretty certain do **not** have post-polio, he doesn't see. Of the 104 possible post-polio patients, 62 were confirmed post-polio and 42 had other diseases. If you wonder "What happened to the 42?" - we didn't say "Well, you haven't got post-polio syndrome. Goodbye. Go home...". No, we treated their problems as best as we could.

With respect to post-polio, there are certain things we **can** do. We can look at energy conservation, carefully graded exercise, and bracing; tomorrow you are going to hear our two most experienced therapists talk about this. Bracing has changed considerably over the years. I see braces now that weigh one third of what they did, for a similar type of device doing the same job, just eight years ago. Because several generations of braces have passed, I can say to a patient "We can now do the same job (as your old braces) with something that doesn't weigh nearly as much". Those of you who had polio or have friends who have had polio, know just what a damned nuisance some of those heavy braces are. Today there are different types of braces, and we can do more things with them.

Seating and wheelchairs have also advanced significantly over the last twenty years. There are now motorized wheelchairs and electric wheelchairs. At one time every person who had a wheelchair had to wheel it themselves. They don't have to do that any more. There are also more resources available. There are today more technicians, more splintmakers, and more orthotists available; and more physiotherapists are interested, and I understand also that there are kinesiologists and physical educationists who are involved.

What has to happen now, and Dr. Petch said it this morning, is the establishment of clinics to which people with post-polio can be referred. One could then identify the problems and refer patients to a local health professional.

I think we need some help from the Ministry of Health. If the Ministry of Health can be as helpful with a group with post-polio problems as it has been with the head injuries people, then I think we are probably well on the way. It wouldn't take a lot, and this is a personal appeal to the Ministry, to be a tremendous help to post-polio, even for just identifying resources, locating people who are available, and in helping us to establish some of the clinics.

Now my last plea will be for you not to be hard on the physicians. I told you that we wandered in the darkness until seven years ago, because we didn't know what post-polio was. A lot of doctors still don't know it exists. I had interesting referral letters. One said "This patient demands that he be sent to see you". I can imagine how it was written, with a fiery pen, in blood (this was in red). But if you say to your family practitioner "Look, there is somebody who, I think, can help me and he is in Vancouver (Victoria, Kamloops or wherever)", I am sure you won't have any problem. Thank you very much.

Walt Slocomb:

Our next speaker is Dr. Charles Simpson. Dr. Simpson was born in Uganda, received his medical training in Scotland, and his neurological training in Newcastle-on-Tyne in England. He is a neurologist and private practitioner in Victoria, with special interests in neuromuscular disorders and electromyography.

Dr. Charles Simpson:

Thank you very much. I am primarily an electromyographer and having heard Dr. Cashman say that electromyography is useless in this condition, I am very tempted to sit down right now! But I don't altogether agree with him. I think electromyography does have a value and I think its value is perhaps not so much in determining between someone who has post-polio syndrome and someone who doesn't, as perhaps determining whether there is evidence of the possible post-polio syndrome or not. I will expand on that a little bit in a minute.

I was very interested to hear what he said about the Macro-EMG, and I intend to see if we can get Macro-EMG available in our area. Electromyography is basically a test in which a needle is inserted into the muscle and you record the electrical activity of the muscle itself.

I want to show you a couple of slides just to show you a little bit of what happens with electromyography in this disease. These are essentially the same slides as those shown by Dr. Cashman but, because they are hand drawn by a simple neurologist instead of an academic who has a medical illustrator to do them for him, they are perhaps just a little bit clearer. Now those motor units (we are looking at the top of them there) have three cells. A motor unit is a simple one nerve cell, the wire that comes from it, which we call the axon, you will see stretching downwards and you will see each one, at the end of its wire, branches out to supply a bunch of tiny muscle fibres. The number of these muscle fibres varies greatly from muscle to muscle.

If you have a power muscle like the quadriceps, the thigh muscle that pushes you up steps, there may be a couple of thousand muscle fibres per nerve cell. If you have a precision muscle like your eye muscle which has to put your eye in precisely the right place (or else you get double vision) then you may have only five or six muscle fibres per nerve cell. This whole thing, the nerve cell, the wire, the axon, the little branches and the muscle fibres, we call the motor unit. The message comes down from the nerve and the muscle fibres all contract; when you have a needle near that activity you will get a simple wave form, usually in three phases.

In polio some of the nerve cells die off. The numbers vary. In some cases very many of them die off, in others relatively few. Now here in my simple drawing there is only one left alive and two that have died off, and as this happens, the muscle fibres, which used to belong to the now-dead nerve cells, are still alive. You will see that there are muscle fibres floating in the breeze with nothing attached to them and in the middle there's one fellow who is as he was before. There is a certain amount of overlap between one motor unit and its adjacent one.

Those little muscle fibres contract spontaneously when they don't have a nerve to control them and they produce very small little electrical potentials which you will see in the bottom right corner: a little spike and a thing a bit like a sawtooth, these are what we call denervation potentials. So when Dr. Cashman talked about denervation he means these fibrillation and positive short wave potentials, which in turn mean that the nerve has been damaged. Now, as he said, those nerve fibres from the healthy motor neuron will grow out and take over some of these floating muscle fibres. The net result of this is that your one

nerve cell there has sent long, thin branches out to all sorts of muscle fibres and, as a result of that, the motor unit has become very much larger.

As a result, the electrical wave form is completely different from the normal one. We see a long, very large, very complex wave form because the conduction along these new thin fibres is slowed, and the territory of it is very much expanded so that we get a complex wave form. This sort of potential tells us that this patient has certainly had old nerve damage. What we think happens in the post-polio muscular atrophy, or the post-polio muscular weakness, is that some of these long, thin nerve fibres which have a long way to go, die off and you begin to get denervation activity again. The territory instead of being very large now becomes much smaller.

When you are missing a lot of motor neurons and you want to increase the power of a muscle you normally have two ways of doing it. If you are just gently moving your finger a few motor units are firing, and they aren't firing very fast. One fires and then another fires and then another fires and back to the first one again. It is not very rapid. If you want to increase the power, you bring in more motor units, and you also fire the ones that were firing faster. If you have had severe polio, and there are very few motor units left, then these remaining ones can't bring in extra motor units because they aren't there. The only thing they can do is fire a lot faster and, in effect, I think what happens is that these units are firing flat out for thirty years, and that is probably one of the reasons that they die. Exactly why they die is not totally clear, but some of these long, thin fibres, that have gone out to other branches, probably pack it in after firing flat out for thirty years.

I am now going off on another tack. I shall be a bit of a devil's advocate here because I have mixed feelings about disease groups - and 'post-polio patients' are a disease group. While "disease groups" provide an enormous amount of psychological support for people, they could also create disease, and that aspect of it bothers me. When people start talking about their symptoms to each other, some people may start thinking that they have something they, in fact, do not have. This creates a problem for us, as not everyone who had polio in the past has post-polio today. As Dr. Bass pointed out, by no means all the people who come in thinking they have post-polio syndrome have symptoms that are really related to polio. They may have arthritis - or a totally different disease, for example heart disease. Or they may just be worn out, emotionally and psychologically done in, from struggling for so many years.

I want to say another thing about post-polio people, which is - I'm just chucking this out as a provocative thought - and I'm going to stop after that. Polio survivors who had bad cases of polio are, in my experience, phenomenal people. They have shown phenomenal guts and strength and spirit. You see some of these people walking around, working with the most horrendous disabilities. What bothers me about today's society is that people are becoming wimpish. In my practice I am seeing an enormously increasing number of patients with WCB complaints, with ICBC complaints, who have next to nothing wrong with them and who say they cannot work and who had no visible disability whatsoever. And I think of my polio patients and I say "My God, there are these persons who have worked for 35 years with a horrendous disability! So what is this fellow in front of me doing saying that he can't work?" And I have a great urge to raise my leg and apply it very vigorously to him.

Two psychological things happen with regard to post-polio. When you have struggled very hard for 30 or 40 years with a major disability, sometimes a person tires out. That is not surprising. It is understandable and it happens sometimes. People get emotionally fatigued as well, and when you've had a bad disability for many years it certainly can happen. The other situation to which it is hard to adapt mentally is: for 30 or 40 years you've been told: "Exercise! Exercise! Exercise! Build up those muscles! Work! Work! Work!" Suddenly, you come in for a checkup and, as the muscle is getting weaker, a physician says to you "Stop! Don't exercise! Take it easy! Go easy! Conserve your energy!" That is a hard situation to adapt to, something which many patients cannot really understand. You've had this tremendous philosophy for years and now you must completely reverse it - this is understandably very hard to accept. People who really need to take it easy should take it easy and the doctor should quite forcefully tell them so. But some people who are not in physical trouble but are perhaps emotionally fatigued, must deal with this aspect and shouldn't take it too easy. They should continue to push. And I am going to stop there. Thank you.

Walt Slocomb:

Our next speaker, Dr. Dennis Galvon, was born in Olds, Alberta. He studied pre-medicine, majoring in mathematics in thermo-dynamics, at the University of Lethbridge. He studied medicine at the University of Calgary, interned with the Victoria General Hospital in Victoria, and was in solo practice in the

Community Clinic on Mayne Island from 1981 to 1983. He completed an acupuncture course at Simon Fraser University in 1984 and has been in private practice in Victoria since 1985. Dr. Galvon did a pilot study on the effects of acupuncture on post-polio syndrome in 1986. He was a presenter to the International Conference in Rehabilitation in Ottawa in May, 1988.

Dr. Dennis Galvon:

Thank you, Mr. Chairman. My own interest in polio, professionally, came about because clients would come in complaining about pain - and I was flushed with early success from this acupuncture course I had taken as I was starting my practice. Naively, having none of Dr. Cashman's or Dr. Simpson's diagnostic acumen, I just thought, "Well, they've got pain." As I examined them carefully, it was clear this was joint pain and soft-tissue pain and some of the important things we look for in acupuncture are trigger spots or fibromyalgic nodules which tend to occur in characteristic places and we can often superimpose an acupuncture chart right over the characteristic places, where these nodules occur. There is a tremendous overlap in the locations of these traditional acupuncture points.

Initially, because my interest was in pain and the use of acupuncture for the relief of pain, most of my acupuncture patients were post polio sufferers. These included the founders of PPASS who would bring me articles to read. I was very impressed with their organization, and also because they brought in multipage bibliographies on polio and were very supportive and nurturing to one another. Furthermore, I found that polio survivors were not whiners. They didn't want very much. They mostly wanted to keep on doing what they were doing, even if it meant pushing harder. Again, this is just the pain-control and acupuncture-consultant side of my practice. I was impressed with how little I needed to do to help post-polio people and how great was their gratitude.

From the general practice viewpoint, however, there are a couple of problems in dealing with post-polio. Polio is not very exciting. It is not really dramatic. It is not THE disease of the '80's and '90's. There is a lack of top down knowledge. As general practitioners, we tend to be taught in medical schools by consultants, by specialists, we tend to do what they say and we try to apply the hospital based training that we acquired. "Let's intervene. Let's cure them with drugs and surgery." And we try to apply that out in the office where probably 60 to 80% of the people have minor, self-limiting problems. They are

not going to need admission to a hospital and probably are going to be made worse by medications and/or surgery. So the problem in general practice is actually "What are you going to do with these people who come in?"

As well, in this acute care/emergency, surgery/drugs orientation that we are taught, there is also a bit of animosity/fear that is trained into you as a general practitioner. You know, guard your own little niche in medicine, be very skeptical of unproven theories, unproven therapies, be a bit of a watchdog over the 'public's good'. You have been taught that "patients cannot possibly know anything about medicine".

Therefore, in a patriarchal sort of way, we are supposed to listen to their 'misconceptions' and their 'wrong' ideas and then gently correct them, give them a prescription, and pat them out the door. This is what we are taught. This is what a GP is expected to do. There is an additional burden that has been placed on him recently by the Ministry of Health and Medical Services Commission, through 'pattern of practice' review, and that is, we are supposed to be the gatekeepers of this enormously overburdened and expensive medical care system. So we are supposed to treat, whoever comes in, very cheaply, simply, quickly and out the door again. No unnecessary costs, no referrals, and certainly no EMG's. I'm sorry, Dr. Cashman, but I just can't refer any patients to you for your Macro-EMG's. They are just too costly. So these are some of the problems that we are faced with in general practice.

There are also advantages to being in general practice. One is that I get to see the patients over and over, and I become familiar with other possible diagnoses and their other conditions, as well as the family situation, and any changes which may indicate additional stress and, therefore, potential physical problems. General practice is a very practical type of medicine. We deal in the possible rather than the proven. I think we have a fair amount of freedom to consult with other allied health professionals and complementary medicine people. So I think there are a lot of advantages of being in family practice.

Problems arise, though, in the dissemination of information on something like post-polio to each busy practitioner. I want to share with you something I just picked up. There is a new national weekly publication called **Family Practice**. It comes to general practitioners and it has very up-to-date news and articles. I was very pleased to see an article entitled "Monitoring Post-Polio Syndrome" in the October 14, 1989, issue of **Family Practice**. It is an excellent article reporting on Dr. Robert Capp of the Loskin Rehabilitation Centre in Regina

speaking at the 35th Annual Meeting of the College of Family Physicians of Canada. He gives what appears to me to be an extremely accurate and well balanced statement of what post-polio is and isn't, the hallmarks of treatment and energy conservation, gentle conditioning exercises and assessment by the appropriate type physical therapists. Anyway, that article was recently on the desk of almost every family practitioner in Canada. They only needed to turn to page 3 and read it. This is a very hopeful sign that, in future, there will be many more colleagues of mine available for you to go and see. Thank you.

Walt Slocomb:

Dr. Stanley Yarnell is a Director of the Post-Polio Clinic at St. Mary's Hospital and has been since its inception in 1981. He is Clinical Assistant Professor at Stanford University School of Medicine. Dr. Yarnell is involved in community service through membership as a Board member of the San Francisco Living Resource Centre. He is on the advisory board of the Disability Rights, Education and Defence Fund. Dr. Yarnell is one of the people who experienced the earthquake recently in San Francisco. We are certainly pleased that he is safe and with us today.

Dr. Stanley Yarnell:

Thank you very much and thank you all for inviting me here. I feel like a real expert. You know the definition of an expert is somebody who comes from farther away than a 50 mile radius and has slides. So you can show the first slide.

I want to begin with sharing some of the statistics that I have been keeping since 1981 in the Post-Polio Clinic. I will run through those as a springboard of discussion. First of all, this is a review of about 386 polio survivors who have come through the clinic and a summary of their problems. The people were between the ages of 30 and 86 years. That 86 year old lady is now 89 and she got polio when she was two months old, so she has been living with it for a long time.

The 'C.C.' in the slide refers to "chief complaints"; and the chief complaints of the various people that have come through fall into the categories of muscular and joint aches and pains, fatigue, weakness, cold intolerance and worsening

respiratory problems. That is why I have always resisted the notion of calling this post-polio syndrome. It really isn't a syndrome in the classical sense of a fixed constellation of symptoms.

In other words, because not everyone gets the same symptoms, I prefer to refer to this condition as 'post-polio sequelae' or 'post-polio related' problems. When I first started seeing people back in 1981, and this was before there had been a number of conferences, the most frequent complaints were pain, fatigue and weakness, and a lot of people back then thought "My God, what is going on? Am I getting polio again?" Those symptoms were certainly reminiscent of polio. I want now to describe what we are finding in terms of the causes of pain. By and large, the pain complaints are related to wear and tear changes or degenerative arthritis in associated soft tissue.

First of all, 99% of all the polio survivors I have seen have scoliosis, an abnormal curvature of the spine. Having scoliosis for a long period of time, and the attendant abnormal bio-mechanics of gait, puts a lot of stress and strain on the low back or on the cervical spine, and it is certainly not unusual that one can develop facet arthropathy. When the cartilage wears down it hurts just like an arthritic joint any place else. This can generate back pain, and cause pain to be referred into the buttocks and sometimes down into the end of the muscles of the back of the legs, depending on which facet joint happens to be involved.

'D.D.D.' stands for degenerative disc disease, and radiculopathy means a pinched nerve root either in the back or in the neck. Lumbar stenosis I found in about 11% of the patients. At first I thought, because so many people had scoliosis and pretty dramatic X-rays of their backs - young people in their 30's and 40's who had back X-rays that looked like they were elderly - I would see more stenosis, but the fact of the matter is the amount of stenosis or choking of nerve roots in the small of the back, generally because of arthritic changes that choke down the space, has been pretty much limited to elderly post-polio patients who were over the age of 60.

Finally there is sacroiliac joint pain - those people who have had some scoliosis have some associated pelvic obliquity where their hips don't quite line up when they are standing and there is some wear and tear on the sacroiliac joint as well. Now, apart from the back of course, there are degenerative arthritic changes in other joints which have been abused over the years. Sometimes this was because of muscle imbalance across the joint, sometimes because, as in the case of the shoulder, it has been used as a weight bearing joint, either through

transfers or pushing a chair, crutch walking or cane walking. This causes problems because, bio-mechanically, the shoulder is not designed to be a weight bearing joint.

The knee, because of muscle imbalance and frequent back-kneeing, and the bio-mechanics of just walking with some weakness about the knee, causes a lot of degenerative changes in the knee. Hip pain, hip degenerative arthritis was next, along with ankle, foot, and wrist arthritis.

There were also a lot of non-articular, meaning nonjoint or non-arthritis, sources of pain, as well as tendonitis or bursitis associated with wear-and-tear changes in the soft tissues.

'C.T.S.' refers to carpal tunnel syndrome, and many of you have heard of it, although it is not exclusive to polio survivors. Pregnant women, typists, computer operators have problems with it; so do jack-hammer operators, as well as spinal cord people pushing wheelchairs around. A pinching of the nerve at the wrist can cause pain in forearm or higher up in the arm, and it will aggravate any other discomfort in the upper extremities if there is some arthritis in the neck. At any rate, it is a pinching of the medial nerve at the wrist and it can cause numbness, pain and weakness. Fibrositis, or fibromyalgia as Dr. Cashman referred to it, has in my experience been associated with degenerative changes in the spine. It can occur to anybody as well as to polio survivors, but the peculiar part is that it hurts in the muscle and not just in the joint or around the joint, but in the muscle belly, and there are frequently tender trigger spots there.

Muscle tension headaches, usually associated with cervical degenerative problems, are not uncommon. Ulnar compress neuropathy is another problem - it is like carpal tunnel syndrome, but it affects another nerve in the arms. Tarsal tunnel syndrome is found in a small number of people, associated primarily with their feet having been whittled on over the years and scar tissue binding up the branches of the posterior tibial nerve of the foot, causing some pain and numbing.

Lateral femoral cutaneous neuropathy is a kind of burning discomfort that some people get in their thighs and, interestingly, this is not peculiar to polio people. Often, fat men who cinch up their belts too tightly get it as well. It is where the nerve comes over the brim of the pelvis, and a big tummy hanging over the edge pressing against a tight belt compresses that nerve. However, in polio

people it was not associated with obesity but with wheelchair users who have a fixed hip-flexion contracture, and when they laid down in bed and their leg started to pull down it was really putting a stretch on all the soft tissue that had contracted at the hip, and it was actually stretching the nerve.

As I mentioned, radiculopathy in a certain percentage of people, and in a smaller percentage of patients, is "thoracic outlet syndrome" which is a problem with pain and numbness in the arms. It was associated with people who had protracted shoulders - folks sort of round-shouldered like this - and the soft tissues over the years got so tight that it was compressing the neurovascular bundle that runs out of your neck under the clavicle, under another muscle here, the scalenus anticus, under the clavicle, under the pectoralis major that goes from here down and out, and became tight when they tried to stretch back a little bit or put their arms up to do their hair or some other activity, and their arms began to get numb, tingly, and painful.

Other people had either joint contractual laxity, a lot of soft tissue tightness, over the years. A lot of you who have some weakness in your quadriceps, difficulty stabilizing your knee, tend to back-knee a little bit and lean forward to keep your knee straight, and this results in the hip getting tight and that in turn can lead to some difficulties with mechanical back pain.

Now to talk a bit about fatigue and cold intolerance. Cold intolerance is sort of a two-fold process, and I do not think that it is suddenly appearing after thirty years. Those of you who had polio, and maybe had residual weakness in one leg, have felt a cold foot for a long time. It has, for some of my patients, become an almost intolerable problem; not a sudden problem, but it has gotten aggravating over the years. This, when added to everything else, is particularly bothersome.

The problem is not arterial insufficiency. If you can envision that this is the artery, the capillary bed here is my fingers, and this is the vein and the little venules on this side, the problem is not primarily on the arterial side. It is on the venous side. For some people who had polio, their sympathetics were affected and they have had all along, some difficulty vaso-constricting on the venous side. When we are exposed to the cold, we vasoconstrict down a little bit so that blood is shunted away from the surface of our skin down to the bone, to keep it warmer. Polio survivors who have what I call "purple feet" syndrome have lost that ability to shunt blood away, by and large, so the foot acts as a radiator. It just keeps radiating heat away from the surface of the skin

and it can get to the point where it cools the soft tissues down to the bone. The obvious thing to do here is to keep the foot warm.

Then we get to the problem of fatigue. My statistics are that while about 76% of people complain about pain, 84% of patients complain of fatigue. They complain of pain but they also have a problem with fatigue, and sometimes they are not sure how much is due to chronic aches and pains wearing them down or to actual fatigue, in the sense of a decrease in stamina. Where there was no difficulty in getting from points A to B a few years earlier, or going up, or down, a flight of stairs with groceries, now they have to rest after five steps before going on.

As Dr. Cashman pointed out, "electro-physiologically" there is a problem we can characterize as "defective neuromuscular transmission". The motor units you see here are shown in colour because there are two different kinds of muscle fibres: white fibres and red fibres. The red ones are Type 1 fibres and the white ones are Type 2 fibres. The distinction is relevant to the problems of fatigue and how to deal with it.

You can keep them straight if you think about chickens. A chicken has all of its Type 1 fibres in its thigh meat and its drumsticks, while its breast meat is all Type 2 fibres. The type 1 fibres are there for endurance. The chicken runs around on the ground all the time and only occasionally flops up into a tree or onto a fence, but it is not a flying fowl like a duck which is red meat all over. So white fibres are good for a short burst of strength and the red fibres are for endurance.

This patient has a Type 1 and a Type 2 muscle fibres and the nerves that are innervating those fibres. Here the Type 1 muscle fibres, that anterior horn cell, that motor unit, had polio and is in the process of dying. In the third panel it is missing and it has left the little muscle fibres fibrillating, without its nerve supply. That seems to set up some sort of chemical distress signal which causes the neighbouring surviving nerve cell to send tiny little sprouts off the terminal axons, the end of the nerve, out to capture those denervated orphan muscle fibres. This is called sprouting or reinnervation.

This is why in polio survivors the motor units became so big and why, historically, when you had first had polio, you may have been profoundly weakened - some of you may have been in ventilators for awhile. After a period of months and years you became stronger. Partly it was because of hard

work and exercise and you were able to hypertrophy (strengthen) those muscle fibres that were there, but partly it was due to the phenomenon of reinnervation, where one anterior horn cell ends up driving many more muscle fibres than usual.

The next slide brings us to the problem of weakness. Related to the fatigue and defective neuromuscular transmission, after a period of about thirty years the motor unit, that is those anterior horn cells, seemed to be having some difficulty supporting all of those individual muscle fibres. Given that there is this defective neuromuscular transmission for almost all polio survivors, the variables I have found are activity and the intensity of the activity, i.e. how many motor units you have left to do what it is you do on a day to day basis. A lot of folks just in their day to day activities, given their number of surviving motor units, feel fatigue. If they stop and rest for a while, they can keep on going, they can gain back a bit of endurance.

There are some who have, over a period of time, actually felt that they have become weaker. In fact, that they are demonstrably weaker can be seen by comparing old records with their physical examination. I now want to review some of the reasons for that. As you can see, not everything is directly polio-related. As I mentioned, radiculopathy or a pinched nerve root can cause pain, but in a few of the people it actually caused significant enough weakness in their already limited muscle, that it affected them functionally.

In addition, of course, polio people are not immune to other neurological diseases. Two people have had multiple sclerosis on top of their polio, one had a brachial plexus injury, and one was lithium toxic.

Finally, the last two problems, acute overwork weakness and post-polio muscular atrophy, which are direct "post-polio sequelae". In some, convalescing from polio, who are engaged in very vigorous activities - whether in weight-lifting, or in tennis - the loss consisted of a full grade or two of strength in a particular muscle group following these vigorous bouts of exercise.

My first encounter with this problem was in 1979, and involved the president of the local independent living project in San Francisco who was quite disabled from his bout with polio, and who basically had one good arm. His good arm, i.e. the sounder of his two arms, was also affected by polio. At any rate, he had come to me three months before this event complaining of weakness and, in a sense, he had a cramp developing back of his shoulder. At that time he was

practically working himself to death at the agency. I did an EMG because I didn't know what was going on; the EMG didn't show anything except his big old polio motor units that are quite clear.

Three months later he dropped his car keys on the floor, and after reaching for them, couldn't get his arm hooked around the back of his electric chair to get himself righted again. He struggled for about 20 minutes before someone came along and helped him to get himself righted in his chair. He returned to his apartment, and fell asleep for 20 minutes. When he woke up he couldn't raise even his good arm high enough to run his electric chair, or to drive his Scott-modified van, and so on. This was a real disaster for him. He came back to see me and we worked him over from stem to stern in an effort to rule out any other more conventional things. He did have arthritis in his neck, but no problem with his nerve roots or with his spinal cord. However, there were changes on his EMG which weren't there previously: the denervation changes that Dr. Simpson and Dr. Cashman mentioned earlier.

I thought, "What is this? Why is this happening?". and that is when I started talking with Dave Weickers - to whom Dr. Cashman referred to before - at one of our Academy meetings. Dave was a resident-mate at Ohio with me. He was telling me what he was finding with his single-fibre studies and he got me thinking about what was going on with Joe, and what could be done about this. I thought at first it represented "post-polio muscular atrophy", as it has come to be dubbed, but after a period of thirteen months resting we got Joe an overhead sling - a deltoid sling - to help him hold his arm up so he didn't have to use his muscles to do that, and so it was easier to feed himself and run his chair. He did an "early retirement" and started swimming.

Lo and behold, after thirteen months he was almost back to where he was twenty-six months earlier, in terms of strength and in terms of his ability to again get rid of that sling, hold up his arm, and so on. That really is an example of an acute overwork weakness. It is reversible with rest, adequate rest. "Post-polio muscular atrophy" seems to be a more insidious and slow process, not in either case accompanied by pain.

I think that the common denominator is the defective neuromuscular transmission. The key variables are: How many motor units you have got left to that muscle; and, the intensity of muscle activity. For those people who have only very few motor units which are powering a particular muscle, for example the motor units to lock their knee, and even if just used in the day-to-day

activity of walking, it may begin to wear out. That is to say, those little (second-time) denervated muscle fibres cannot be recaptured by that nerve cell again. The remodelling process, that Dr. Cashman was talking about, is not able to go on again because the whole nerve is being so overworked it can not support sprouts coming back out and recapturing the newly disconnected muscle fibres. This is not a reversible process. No amount of rest will bring the muscle back.

That understanding has, I think, led us to some ideas about conserving energy and dealing with exercise. You can see that, of the 57% of the people who complained of weakness, it was the acute overwork weakness of post-polio muscle atrophy that makes up the bulk of that weakness.

Incidentally, there is a handout. It is a reprint of an editorial that was in the June issue of the **Journal of the American Medical Association**: A brilliant article by me!, with references to Drs Cashman, Dalakas, Weickers and Perry. I have today tried to recapitulate some of this material a bit more succinctly.

I just wanted to say one other thing and that is about respiratory problems. People who have not had respiratory problems to begin with, generally are not getting new respiratory problems now. It appears to be people who have had initial respiratory problems, whether they were in an iron lung or not, who over the years may get in to some problem of worsening respiratory function. Whether this is because of the scoliosis and fixed chest wall deformity, or the particular group of muscles that they have breathing with, still needs to be checked carefully.

To reiterate, the problems are: muscular and joint aches and pains, and fatigue. Closely related to that, in some cases, there may be weakness (which is reversible with rest), worsening respiratory problems, and cold intolerance. These is the most common constellation of symptoms. Thank you.

II. FACING FINANCIAL ADJUSTMENTS

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Stewart Johnston (Moderator), Lawyer, Victoria, B.C.

Alex Burnell, Chartered Accountant, Victoria, B.C.

**Pat McGuire, Retirement Planner with Sun Life Assurance Co.,
Vancouver, B.C.**

**Bob Hunter, Chartered Financial Planner with Investors
Group, Victoria, B.C.**

Stewart Johnson:

I practice law in the City of Victoria, with the firm of Horne Coupar. I have been involved with PPASS for more than three years now, giving a bit of legal advice here and there, and I've followed your society with great interest.

Alex Burnell:

I am the Auditor for PPASS. Like Stewart, I have been involved with your organization almost from its inception.

Pat McGuire:

I have been with Sun Life for five years now. My area of expertise is in the field of Retirement Planning. I became involved with post polio through Corrections Canada, as I am under contract to provide retirement planning services in the area of Retirement Planning for Corrections Canada. One of the people in a recent seminar I held with Corrections is involved with post polio and had suggested I get involved with this group to offer some help with financial planning.

Bob Hunter:

I am a Financial Planner and have been with Investors Limited for fifteen years. Prior to that I served for fifteen years with the Bank of Montreal. I am here today because Rheta Davidson asked me. The first I heard of your organization was through reading your pamphlet. I hope I can be of some help to you.

Stewart Johnson:

Considering the time constraints, let's have an open forum here, and get straight to the questions. If you would write down your questions, the panelists will try to answer them.

Question: How do you figure out how much you should have for retirement? What is your formula for figuring out how much you should put away each year towards your retirement?

Answer: This is the 5-minute financial planning. I'll draw a big circle - savings, investment, insurance. The #1 priority is Savings. #2 priority - Investments. #3 priority - the worst investment in the entire world - Life Insurance. It is used purely as a balancing mechanism on Savings. You should look at 10% of your income going to savings on a regular basis, and 90% of your income going to investment.

Question: Did you say 90%? What are you going to eat with?

Answer: That's what you are investing in, yourself, in your holidays, in real estate, in mutual funds, stocks, bonds, whatever. Savings is purely your daily interest account. You should look at typically 3 months of savings in a daily interest account, that is liquid money and on hand for emergencies. It can be made up from your savings account and it can be long-term makeup through insurance. You start as quickly as you can by building three months' savings. From that point, any extra dollars should be invested in long term investment.

Question: So, after you get the 3 months, then the other money that you save you put into long term, is that what you say? Not RRSP?

Answer: An RRSP can be a portion of that. The Government of course giveth, and the Government taketh away. The rule book is changing once more. Seniors, OAP, CPP could be rolled into RRSP's if you didn't need the income, but it would be further taxed at age 71 when we must take it out. As of 1990 that is being blown away. That income no longer qualifies for RRSP. Formerly you could put savings away in a deferred annuity certificate and not report the income until you started to take it out, perhaps as a blended payment, so you lowered your tax report. That too goes as of 1990. You can calculate up to a 3-year deferral until the end of 1989. After that it is gone. So the government is basically grabbing wherever it can. As far as we are concerned, everyone has a comfort zone, so you want guaranteed securities; you want your income securities, which are your dividends, and you want some capital growth because you are allowed \$100,000 tax free. At one time they had an idea of raising capital gains to \$500,000, but they capped it at \$100,000.

Question: Relate this to polio survivors. Assume a couple have gone 30 years with no problems, the bread-winner had polio and suddenly starts coming down with symptoms. What adjustments in the financial picture can happen? At what point does an insurance policy kick in and, if you are incapacitated, you will say "we will pay out your whole life insurance policy and start making payments to you? What is covered under B.C. Medical for equipment, wheelchairs, and so on? Is there any way to collect Canada Pension early in this situation, for instance?

Answer: I'll try to answer those questions one by one. Regarding the insurance policy, as to when you can collect, if you were in a situation where you were disabled you would have a permanent insurance policy which would have equity growing in that policy. Typically, a lot of people are in a situation where they will cash out the policy and take the equity and, sadly, that is probably the worst thing anyone can do with an insurance contract, because you may have an insurance policy, as example, that has a \$20,000 equity built up in a \$100,000 policy. Instead of cashing out the policy, you can borrow the dollars out of the policy, usually at typically the prime rate + 2% if the policy is of the type of today's new policy. If it had been bought ten years ago and earlier, usually it has a locked-in interest rate around 5% or 6%. So you could borrow the \$20,000 out @ 5% or 6% and never be in a situation of paying that

loan back, because the loan would be subtracted from the death benefit on death occurring.

If you take the money out by borrowing, the death benefit does not stop growing, because the dividends are causing it to grow. Let's assume the person borrows a \$20,000 amount at 10% over ten years, you are then looking at another \$20,000 of interest payments, so the debt owing would be \$40,000. But a \$100,000 insurance policy has been growing at the same rate for the next ten years, so the \$100,000 policy may be worth \$150,000 at that point, which would leave a death benefit of \$110,000. So my advice is, don't cancel the policy if you need cash. Borrow against the policy or, if you wish, just ask for the dividends. You can take the dividends directly out of the policy and it won't affect the policy, and it won't affect the death benefit.

Question: Does the federal government have any provision for taking Canada Pension Plan benefits early?

Answer: Yes. Basically, when you are disabled you can collect Canada Disability Pension. There are several guidelines and I understand they are very serious and critical guidelines. It is difficult to receive, and I am not an expert in that area. For the Canada Pension Plan, they want to know "do you have a permanent disability and is it either physical or psychological in nature?" Also, it must be well-documented and backed by medical opinion, in which event you should qualify for a disability pension. There's a 4-month waiting period. The pension itself is rather inadequate, a maximum of \$681.00 per month, but that could be helpful to a disabled person.

Question: Can you earn money on the \$681 - reinvest it?

Answer: I think you can earn a bit more, but I'm not sure. If you have dependent children up to age 18, or even to 25 if still in full-time attendance at school, you can get \$103.00 per month support payments per child. It may also be retroactive for a year or two, as well. But I recommend if you want the Canada Pension benefits and if you have "coverage-in-place" when becoming disabled, you contact the Insurance company. Ask them to contact their Rehabilitation unit and get those people to do the leg work for you, to find out the answers regarding Canada Pension, Old Age Security and that type of thing. Use them. It's free.

Regarding Canada Pension Plan, Welfare Canada has a number of Canada Pension publications covering disabilities, survivorship, etc., and you can call them by telephone or visit their offices. They're helpful. You can start drawing Canada Pension Plan at age 60, but you sacrifice 1/2 of 1% per month, which would reduce your CPP 30% below the 65-year age level. If, however, you don't draw Canada Pension until age 70, the premium increases by 30%, but you also receive 130% of the maximum.

Another important factor you should be aware of is, if you and your spouse have each contributed to CPP at two different earnings levels, assume one spouse receives \$500 per month and the other spouse receives \$100 per month. You can apply to "pool" the two pensions so that each spouse receives \$300 per month. This can be very important if the two of you are in different tax brackets and it can result in very substantial savings. Upon the death of one spouse, you can revert back to the other amount. If you have questions about CPP, you'll find Health and Welfare very helpful.

Question: How long will that disability pension last?

Answer: Until your regular Canada Pension Plan kicks in. I have one thing to add, something that starts in January 1990. You can be in a position where, if you pay too many tax dollars, you can roll over a disability income into your RRSP because you are disabled. If you are not disabled you are now denied that.

Question: If you receive disability pension, is it taxable?

Answer: Most disability pensions are non-taxable. CPP is reportable but in some cases ends up not being taxable. CPP is basically taxable income, although you may have enough tax credits to offset actual tax liability on that income.

Question: If a woman is working full- or part-time and earning a good income and her husband has a good income, what happens if the wife becomes disabled and unable to work? Does the government penalize her for being married and being supported by her husband?

Answer: Her disability pension is governed by her contributory earnings. They have a flat amount that all disabled people receive, and anything above that amount is based on the contributor's history of contributions since 1966, the year the Canada Pension Plan was introduced.

Question: Then you are not penalized for being a woman and married?

Answer: No.

Question: I'd like to know if there is a federal government tax break for handicapped people. Are you familiar with the form for it?

Answer: Yes. I have one.

Question: Okay. I saw the form and said to myself "Well, it doesn't look like you qualify - they don't have to carry you into the house at night." What does the form mean?

Answer: That is a relevant point. The form this gentleman refers to is called a disability credit certificate. It is Canada Revenue form T-2201. We've had a lot of clients file this form and had their application delayed. The doctor says in certification area "In my opinion the disabled person named above has severe impairment (check yes) which is prolonged (check yes) and as a result of this impairment this person's restrictions in the activities of daily living are mild or moderate."

Revenue Canada cannot assess whether it is mild or moderate; they have 15,000 applications. As a result, Revenue Canada was responsible for apportioning this but does not have qualified medical people to make the determination.

Temporarily, therefore, the matter has been turned over to Health & Welfare Canada. If you have not received it or your refund check, there is the backlog of the 15,000 applications. If you can convince your doctor to check the certification as a "marked disability" it will really speed up your application dramatically. If the condition remains in the "moderate" class, then Revenue Canada will deny your application and tax credit.

Question: What is the name of the policy form?

Answer: Disability Credit Certificate, Ref. T-2201. If you find you are eligible for 1989 tax year and have not filed it in the past, you can file it at the time your tax term is due which is April 30, 1990. This is the \$3200 tax credit which converts to \$1500 of tax savings - a provincial legislation I can't comment on, but it is strictly for filing personal tax returns, and was basically written for those who are severely restricted. Because it extended to a large number who don't fit that real category, Revenue Canada tries to stick to the guidelines of daily living activities as categorized on the back of Form T-2201. But your eligibility lies with your doctor's diagnosis and opinion. If you don't agree with what your doctor does, perhaps the only solution is to change doctors - some don't believe in post polio problems. Find a doctor who knows about it.

Question: What about insurance? Where I work we have insurance for disability with Sun Life, I think. On the form it says: "Have you had any serious illnesses?" Well, I write down I had polio. Doesn't that invalidate any disability from post polio syndrome, because you've already said you had polio?

Answer: (Pat McGuire) Most major insurance companies have a definition of a pre-existing condition within the last six months which wouldn't be covered. But if you had polio two years ago it would be covered. There are some who represent insurance companies who don't listen and who do not provide proper advice - so it is best to go over his head to somebody higher up in the company. After all, the best marketing an insurance company has is honesty and sincerity in paying legitimate claims. The business works on the principle that we are going to pay when somebody becomes disabled or dies.

Question: What is a good investment for family allowance cheques.

Answer: (Bob Hunter) Good question. One investment is with mutual funds which are primarily a portfolio of securities - that is, instead of lending money to the banks we buy the bank and participate in the profits - and I don't think anyone here doubts a bank isn't going to make a profit? There are two factors. One, there is the income that results from holding securities, known as dividends. If you buy Canadian companies, the government gives you a break on the tax credit. In this case, you want capital growth, so you look at

portfolios dealing in that area, where the company is purchasing quality common stocks.

Question: I thought mutual funds were for long term investment? I was thinking of an investment until my son was old enough to go to university. He's eleven, now.

Answer: So basically you have eight years. Any investment period over 5 years is a reasonable time to get involved with investment funds. Less than 5 years you are looking at income funds - funds that pay more to shareholders and not capital-builders. But for young people, for the long haul, the capital portfolio is what you need, because your rate of return should be 1 1/2 to 2 times what you receive out of a bank account, because you are "owning" rather than "loaning". As an example, if you lend money to a bank, credit union, or trust company you are saying "Here is my money. Give me x percent". They will give you what they feel is reasonable and they are going to put that money out in investments, take off their operating costs, pay you the guarantee, and keep the profits. But if you invest in the bank or company yourself you will get the profits.

Question: Are mutual funds as safe as bank accounts?

Answer: You'll have to qualify "safe".

Question: If my \$100,000 in a credit union is put into mutual funds, do they guarantee cash back if there's a market crash?

Answer: No, there's no such guarantee. Your mutual fund is an investment, not a loan. It is an investment in a broad range of corporations and companies in the ownership of which you are participating. You may know that, contrary to popular belief, 1987's Black Monday - and Friday 13th this year - did not "crash" mutual funds. The Equity Funds were the ones that crashed. You should consider, perhaps, that the mutual fund has virtually 100% security because mutual fund portfolios are made up of **combinations** of investments.

Question: I could say "I'll put all my money in a mutual fund and in ten years I'm going to be laughing," but suddenly all my money is gone because something happened. Should I have put it in another kind of mutual funds? Is that what you are saying?

Answer: It is "buyer beware" with mutual funds. First, you don't buy a mutual fund for the short term. By law you must be given a prospectus, which is designed to explain the objective of that fund. If that objective does not meet the criteria you set for your money, you shouldn't consider it.

Question: What are we talking - 8% or less? Better than bank savings?

Answer: No, more than that. And yes, they are much better than bank savings. The real crux of this issue is that your mutual funds in the capital growth and dividend areas are not paying as much tax as an interest-bearing investment such as bonds, mortgages, the money market.

Question: There is one thing on your brochure relating to the RRSP. Will you explain that one?

Answer: With an RRSP you save taxes, but on a deferral basis - you are building your own pension fund yourself, so you can take a tax deduction for your current tax-year RRSP. For the long haul, it makes a difference as to which product you choose, RRSP, GIC, Mutual Fund, Bank Savings Account, Money Market, or investment fund. You look at a thing called "dollar cost averaging". Regardless of what the market is doing, up or down or even, your dollar is going in systematically, and dollar cost averaging will make it more profitable in the long haul if you believe your "ownership" will keep up with inflation. GIC Insurance is lowest on the scale of safety. If you have a Mutual Fund, you don't have to continue to roll over the earnings on it - you can take out whatever you want to. The GIC is a term deposit which will pay you the interest at the end of the term of the certificate.

Question: What is the relationship between part-time employment and fixed income - legally and accounting-wise? How much part-time employment can you have to supplement your income?

Answer: If this is relative to Social Services such as GAIN, the different programs have different policies and different numbers. With GAIN, you are entitled to earn a small amount more, but as you exceed the established government maximum for earnings, any excess is deducted from your GAIN cheque issued by the government.

With certain disability insurance pensions, you are encouraged to rehabilitate yourself and re-enter the job stream in another area of endeavor for up to 2 years. That is, the rehabilitation program allows you to earn an income, the insurance company usually provides a period of reduced premiums in which you receive partial payments. Insurance companies classify and define occupations that are involved in a company's specific Group Insurance Plan.

As an employee, you are recorded as being in a specific occupation. Should something occur to cause disability, for example, as a baker you become allergic to yeast, and you are categorized as disabled, i.e. unable to work in your specific occupation, you would receive, say, two-thirds of your normal income from the Group Plan. You could go across the street, get another job with another designation - and you would have two incomes. At the end of two years, the Insurance company would now say to you "You are no longer eligible for income as a baker. You are now categorized in the latest occupation you have had. The Group Insurance Companies have categorized 1,823 different occupations in Canada.

Question: There is a person in my Area Group who phoned me with quite a problem. He is on disability pension but he doesn't wear a brace or other visible disability thing. He is on Total Disability and on a Government pension, but he's afraid he doesn't qualify for the T-2201. Does he?

Answer: The T-2201 was designed for the person who is unable to do personal care activities such as preparation, serving and eating a meal, dressing, washing, personal grooming. But because of the nature of disabilities, and because of many ambiguities in T-2201 criteria, many times more partly disabled people have qualified. I suggest that your friend go to his doctor, who has to fill in parts of the form anyway, and who has to sign the form to make it legal. If you experience difficulty in claiming for disability because your doctor doesn't consider you as having a disability, my personal recommendation is that you get a second opinion. You've been paying for these benefits and if the insurance company considers you disabled and unable to perform the duties of

your occupation and pay you, I am sure they would advise you to get another medical opinions.

Question: Is there anything in the Income Tax Act as far as becoming partially disabled? I can no longer hold the telephone up to my ear. Could I be covered for that sort of disability?

Answer: Surprisingly enough, Taxation Canada has expanded the areas of qualified medical deductions. There is still the problem that you have to take 3% of your net income and subtract it from your medical expenses. There is a part where you can get a tax credit, but you may have difficulty qualifying for a deductible expense. But you might want to save up these tax credits to achieve a maximum amount in any given 12-month period. If you are spending money on buying a medical device outlined in the Income Tax Act or in other Revenue Canada publications - or from Accountants like myself - you can save a lot of tax dollars by the appropriate timing of the purchase of these devices. Just make sure you fit it into the right taxation year.

Question: I have been on a post polio test program for which I had to buy a special electric muscle stimulator. How can I best apply it to alleviate my tax bill? I have my doctor's prescription for it, and the receipt for it.

Answer: Get a certified letter from your doctor which should automatically allow the deduction.

Question: If I take out \$1,000 from a mutual fund, does it have to be a specific type of mutual fund?

Answer: Most mutual funds allow you to take what is called a variable income out of them.

Question: Without paying any tax?

Answer: Your tax has nothing to do with the amount that comes out. You're taxed according to what type of investment you have. You are selling "units". When you sell a unit you will have capital gains on that unit, and under the

capital gains legislation you will be taxed on any dividend income from whatever portfolio for that year's taxation.

Question: So it varies, depending on what mutual fund you go from?

Answer: The tax law is changing again, and for anyone who has the luxury of having a pension you don't need, who has other sources of income and has been used to rolling them into RRSP's, as of 1990 it is a new ballgame. You can't roll them over any more. So the government is making another grab and hitting Seniors or those on Disability Pensions. For 1989 and for 1990 through 1994, you are allowed to put \$6,000 into your spouse's account and to build her account, because 2 incomes generally pay less than 1 high income. The 20% rule, of course, still applies. So, in the '90's people are going to be looking for the dividend capital growth area because there's nothing left to shelter.

Question: What would you recommend for Seniors?

Answer: A Senior should automatically consider being conservative, staying with bonds and the like.

Question: Concerning Canada Pension, some of us are not of retirement age and are having post polio problems. We are reduced to, at best, part-time work and our income is going to be quite variable, so we may not be paying the full Canada Pension deductions. How will that affect drawing a Canada Pension 10 or 15 years down the road?

Answer: If you start drawing Canada Pension before age 65, there's a 1/2 of 1% per month penalty, which at age 60 would reduce your maximum pension by 30%. They allow you certain exclusion periods. Canada Pension commenced in 1966. It has a moving average. For such details you should ask Revenue Canada or Health & Welfare Canada for a projection of what your pension will be if you are to exclude or if your earnings were to drop. They have a contributory history report which you can ask for every 3 years without cost, and it will give you an idea of the impact there would be by the lower period of earnings in later years.

Question: That's a problem many of us are facing quite early, long before we are ready for early retirement. Eventually my job won't be available to me, so my earning ability will be much less, long before I'm ready for early retirement.

Answer: Unfortunately, the maximum for 1990 to be able to put in the maximum pension credits is around \$29,000. If you find you're trying to maximize your money over the shorter earnings career due to disability and facing too-early retirement, one good piece of advice is "pay down your mortgage to own your house before retirement", because there is no governmental desire to tax your principal residence. You could also seek out a financial planner or chartered accountant and get some really good advice as to where to put your eggs, and in what baskets. For example, if you have some cash available and you don't know whether to use that to pay down your mortgage or to go into another investment, you can pay down the mortgage on your house and then turn around and take out a second mortgage, an equity mortgage or something like it, then apply that money to the investment, and you can write off the interest on that. That's a tip from a chartered accountant.

Question: Then the best savings you can make is pay off your personal debt or personal mortgage?

Answer: Depends on your mortgage. Here's another piece of good advice for you, "Don't take financial advice from a lawyer!" Another area you can look at is the "Registered Education Savings Plan. You can put money into an education savings plan, and name yourself as beneficiary, rather than your children. Those monies are able to grow for 21 years before they have to be collapsed and used for an educational purpose. That can include, and this has been documented by our company and likely by all those in the investment industry, a university course in Hawaii. The cost would include transportation costs to get to and from university, and you do require housing. It's an option.

You are allowed to put up to \$30,000 each year into it. You can do this on a monthly basis, or through a mutual fund, or a lump sum deposit. This will grow over the years but it will only be taxed when the monies come out. If you are, say, 44 years old, you've got 21 years before that money is used. Why not use that for the start of your retirement income? Start taking some courses around the world or wherever?

Question: You can put away money toward your own education, not just your child's?

Answer: Yes. And you can transfer beneficiaries at any time, also.

Question: There is another point I want to bring up. It's in connection with the accident I was in. The doctors are saying I have an underlying condition, which is true, but without that accident I may not have suffered the problems as soon as I did, or may not have suffered them at all. I'm sure there are others who are going to have this problem at some stage of our working career where we have a weakness and we now learn that some trauma could cause it and bring it on sooner. How can we protect ourselves in this case?

Answer: You get a lawyer.

Question: I can't afford a lawyer.

Answer: Well, there is legal aid. There are clinics and lawyers who will do things cheaply. We all have our favorite charities and will take on the odd case out of "pro bono" feeling.

Question: Aside from legal aid for which we as working people don't qualify because we make too much money, how do we get in touch with the people who are involved in the kind of things that you mentioned?

Answer: You can phone the Lawyer Referral Number - you'll find it in your phone book - in the Yellow pages - under Lawyers. You can also phone the Law Society. Both organizations can help point you in the right direction.

Question: I've talked also to a few people - not just Post Polios - who have been involved in the same thing?

Answer: The concept you are talking about is known in law as the "Thin Skull Problem" and if you're a person with a condition such as a thin skull - from the original case that gave it the name - from involvement in a car accident, etc. it

doesn't matter whether you had the pre-existing condition because the negligent act occurred to you and it caused you this problem and so there, at least, the pre-existing condition is not a problem. You are going to need to find your way clear with medical experts and good legal assistance to convince the various appeal levels that, in fact, this accident brought about your problem and that the pre-existing condition did not. Secondly, that the pre-existing condition would not have come about until later on and so you are suffering a problem because of this accident - industrial or otherwise.

Question: I couldn't anticipate this as being a problem for a lot of our Post Polios because one doesn't know when one's condition will start nor what will trigger it.

Answer: It comes down to medical opinions, and you'll have to shop for a doctor. In a lot of cases, for example, an ordinary person who had their leg broken through somebody's negligence, six months from now they'll be probably all right.

Question: I was in an accident. I had Polio when I was one year old. I have had polio effects all my life. They try to prove that the residual effects of that accident did nothing to me and wouldn't bother my existing polio situation. There was no precedent. What I want to know is how you change the court ruling. How do you get "precedents"? You have to have a judge, is that not the case? You have to have a judge to make a whole new decision.

Answer: Or a tribunal. But yes, a decision maker.

Question: At the time, and as far as I know, the 'late effects' of polio have just been recognized as the post polio syndrome.

Answer: I'll bet it's not, too. I'm saying, however, this girl and the rest of us must do more than just talk to you. We must see that something is done at the judgmental level.

Question: We have to lobby?

Answer: That's right - education and dollars. I mean both. Because if it happens to you and you go through the legal battle, the judges and courts are not going to shrug because there is no precedent and not make a decision. They are going to make a decision and if you don't like that decision the only thing to do is to appeal to a higher court. And if you don't get the decision you want at the end of the day then you've got to lobby.

Question: What about "Class Action". I don't know much about it. Is a class action one way for all of us to band together and go as a group?

Answer: Not in an instance like this. Not all of you have post polio syndrome, yet you all had polio, all been wronged and all have the same case. The "Delcon Shield" is an example of a class action where a great number of women were wronged by the same negligent act. This enabled them to bring their action together.