



ONTARIO  
MARCH  
OF DIMES

PROCEEDINGS OF THE  
ONTARIO MARCH OF DIMES  
ROOSEVELT POST-POLIO SEMINAR

JUNE 1, 1985

ONTARIO MARCH OF DIMES  
60 OVERLEA BLVD.  
TORONTO, ONTARIO  
M4H 1B6



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## FOREWORD

With the identification of the Late Effects of Poliomyelitis, the Ontario March of Dimes has returned to its original mandate of serving people disabled by polio, by initiating the Post-Polio Program.

This program operates under the direction of the Post-Polio Committee of the Board of Directors of the Ontario March of Dimes.

The Ontario March of Dimes Roosevelt Post-Polio Seminar held in Toronto, Ontario on June 1, 1985, represents an effort towards the goal of increasing awareness of Late Effects of Poliomyelitis on the part of persons disabled by polio as well as members of the medical profession.





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**U.S.A. AND CANADIAN OVERVIEW OF POST-POLIO ISSUES**

**A Panel Presentation**



It is a great pleasure for me to be able to be in Toronto and to take part in this gathering. I learn something almost every time that I come to Canada. When I have the opportunity to visit with people who are so dedicated to doing something which so badly needs to be done, I always go home with the feeling that no matter what effort you put into it, it isn't nearly enough.....

Really, as far as I was concerned, polio, for my father, at least, was an open opportunity, something that gave him a chance to broaden his horizons.

As time went on and the opportunity came in 1933 to assume the helm of the country, it was because he had been able to do so much groundwork - had been able to spend the time. One of the things that I'm sure he would smile about was that he did have the time. That he was able to give the time to reflection of what was needed and to the conferences with people who he felt would make a contribution to the so-called New Deal Program, really resulted from the fact that he did have polio. So it was, in a way, for the country at least, I think, a blessing in disguise.

I think it is fair to say that the other thing that has fascinated me was that he always believed he would be able to walk again. Even though when he first had polio, walking was very difficult - the braces on each of his legs weighed ten pounds apiece and it was difficult for him to walk any great distance - yet in the back of his head he thought that if he could only get down to Warm Springs and spend enough time there, he would be able to walk.

At that time, however, they did not know enough about how to do nerve regeneration. Now they are so close to doing it. It is such a hopeful thing that I realize that his hope that he would be able to walk again was not completely vain or false. That it didn't come to pass, that he did not see the polio vaccines as they came along in the fifties, I'm sure was a disappointment to him, but would have given him great happiness and a great feeling of accomplishment had he lived to see them.

What is open now to all of us and the work that lies ahead, particularly in the two fields of recurring polio symptoms, I think are things which he would have been tremendously interested in. But I can't help but think that perhaps the thing that would have interested him most was the fact that in the developing countries still, because of the inability to get a marketing program or a distribution program of immunization throughout these countries, there is an incidence of polio that is far higher than anything in the United States ever was. The fact that there are children who are dying every day because of the lack of care that we can reach to them, presents a challenge to us which I am sure he would have wanted us to carry on and to do the best we could with.

So I am happy to be a part of this panel today. I'm going to leave it to the experts to make the contributions, but I just want to say that I know, as a part of my family history that he would want me to wish all of you a great deal of luck and to say that he looks forward, wherever he is, looks down on us, to the day when things will be so much better than he ever dreamed of in his time.

## THE ROOSEVELT WARM SPRINGS INSTITUTE FOR REHABILITATION

Thomas Gaines

I am not going to have a lot to say except to let you know that the State of Georgia is totally committed to doing anything and everything that we can as a government organization to further research the late effects of polio, to do what we can to market the need world-wide for a networked immunization program, to seek funding for research, training and treatment. We will use the Roosevelt Institute as the primary vehicle for that.

As some of you probably know very well, the Roosevelt Warm Springs Institute for Rehabilitation was begun by President Roosevelt as a centre for polio treatment. We have continued that, but we have added quite a bit over the years. It is now a multi-dimensional program that focuses on medical, vocational, educational, recreational and independent living activities. We have just recently added a Head Trauma Treatment Program at the Institute and an Industrial Injuries Centre. It is quite a large complex.

Our primary objective for the future is two-fold. One, is to establish the best rehabilitative centre in the world, bar none. We will achieve that. The State of Georgia and the Roosevelt Foundation are solidly behind that objective, just as they are the other part of that objective which is to participate in the establishment of a worldwide linkage where we can exchange staff, exchange information, do treatment and do research worldwide.

We're very excited about the future. I hope you will understand what I mean when I say we are also very excited about learning more about Late Effects of Polio. As many of you know, the incidences of new polio cases are really growing worldwide. We have heard from many individuals around the world about the epidemic proportions of polio now.

I bring to you a word of commitment from the State of Georgia that we are going to continue doing everything we can to further the tradition of President Roosevelt and what he began. We look forward with much excitement to our budding relationship with the Ontario March of Dimes, and perhaps with the Lyndhurst Centre and others here.



The Georgia Warm Springs Foundation was founded by President Roosevelt. From day one, the philosophy there has been one of being concerned about the individual and the family. That philosophy still exists today. We have tried to develop a total theme process to addressing the needs of all persons with disabilities in a way that we address the individual concerns.

I am impressed with the type of things that are going on with the Ontario March of Dimes. Those of you that come from the polio background realize, I am sure, that a lot of programs have forgotten the needs of those who have had polio. I believe the Ontario March of Dimes is trying to address that particular issue. More importantly, in The Advocate they state what the program goal of the March of Dimes is really all about and that is to give greater meaning, dignity and independence to those whose lives have been affected by disability. Those of us in the profession need to keep that in front of us all the time. It's not the bricks and mortar that really count in the final analysis, it's how we relate to each other as individuals. One of the things that I continue to try to remind myself and my staff at the Roosevelt Warm Springs Institute is that if we ever forget that we are working with individuals and get so preoccupied with some of the other things, we will be in bad shape.

We feel that we are developing a good program there. We think that we should become a hub for the activities involving the Post-Polio Syndrome, as some people are calling it. We prefer to call it the Late Effects of Poliomyelitis. We don't refer to it as "old polios". That's not a very good thing to say.

Let me just give you a little background on what has happened in that regard. The Institute was probably one of the first places that started getting some inquiries from people all over the country and around the world who had polio, describing certain problems and asking if we were getting any inquiries. We started looking into it in a fairly intensive way about five years ago. As we started bringing in people to visit our program, we noticed some things that seemed to be fairly uniform.

About three years ago we at the Institute started saying, "Hey, you know, this really is something, there is something going on, but we aren't sure what it is." Unfortunately, or fortunately, speaking personally to those who have had polio, you did such a good job dealing with your problems that the medical community had really become unaware of your problems. We were hearing all kinds of things: "I can't find a doctor that even knows what I am talking about." (Patients were told:) "You'll be all right. It's probably something you were thinking about. Don't worry. Go on back and forget about it."

On the other hand, we had no data base to really document whether or not there were problems. We decided it was time to try to get more specific about some of the things that were going on.

In cooperation with the medical community throughout the world and with the support of the Warm Springs Foundation, we decided to host a conference last May, to which we brought about 40 of the leading physicians, including some from Canada, to come down and share with us and each other what they were seeing with this particular problem. The results of that Symposium have been published in a book entitled **Late Effects of Poliomyelitis**. It is available for a slight cost. We will leave information and forms with the Ontario March of Dimes if you would like to purchase the book. It represents the state of the art as far as the medical profession was concerned last year, at least the ones we were in contact with, on what they were seeing.

As we worked on this problem, there were several things that came about. First, I want to emphasize before talking about specific problems of the Late Effects of Polio which really concern us, I think I need to say something else that I think should concern us all even more. That is that the programs - the Salk vaccine and the Sabin vaccine - have in many ways been a victim of their own success. Unfortunately, we can really rally around a problem, we can really address it, we can go after it and get everything squared away, and then we have short memories. We forget that the potential of polio still exists as a real problem. In the third world countries it is in epidemic stages in many places. In our country we have only to go across the border to Mexico. Mr. Roosevelt is very much aware that not too far from where he lives in California in recent months there have been over 40 new cases reported.

One of the concerns that came out of this study was that we needed to get into a preventive program because the ultimate rehabilitative program is one that prevents the disability to start with. Clearly, we felt that we needed to try to be a catalyst for working with many other organizations, Rotary International, UNICEF, and many others, that are trying to address the problem of immunization worldwide, not only in polio but other disabling diseases. We saw that as something we wanted to do in cooperation with the Foundation as a part of our new program. We are going to be addressing that issue in more specific detail.

Getting back to the Late Effects, we discovered at least in our situation, one of the things that we had trouble with was not really having any firm data base to work from, to try to decide what should be done. While there were many issues that came out of the Symposium, one thing was the need to establish clinics throughout the country and the world in which we could start gathering data to see where things were at the present time.

There are several around the country and here in Canada, and there certainly need to be more.

What we elected to do was to establish a rather comprehensive five-day evaluation program at the Institute. It has continued to be changed as we have worked with it. The program is two-fold. It tries to get some common understanding of what this issue is, what the problems are. I would like to share with you what our findings are up to now and say that we aren't going to have much data and some firm information until we have had a chance for those people that have been through the evaluation to come back in a year or two years and let us do another evaluation.

Most of my information relates to the United States, but in the last issue of The Advocate there is a rather detailed analysis of some research that has gone on here. It is a summary of the Ontario March of Dimes Survey. Our findings pretty well parallel what has been found here. We have determined that there are 300,000 former polio patients living in the United States. We did confirm that there is a real problem that needs to be addressed. It is probably not life-threatening. Our data indicates that about one-fourth of the post-polios have some type of problem. The data that has been collected in Ontario indicates about a 15 percent factor. The data is probably skewed a bit because those that have the problem are the ones that are coming forth. We find the ladies are more willing to work with us than the men. I would encourage the menfolks to get a little more involved. What we are talking about is that former patients experiencing this problem number in the tens of thousands, if not hundreds of thousands, of people.

Most of the symptoms include increased fatigue, weakness in the polio and non-polio affected muscles and joints. In many cases severe pain is associated with that. Many times we find the best recommendation is a change in life style. Sometimes this may mean a return to braces or to the wheelchair or aids to the system of breathing, that many of those who had polio had put away a long time ago.

There seem to be two schools of thought. One is that there is premature aging of nerve cells, damaged by the early polio infection. The age of the polio patient does not seem to have anything to do with the problem. It is the length of time since the onset of polio. What we have discovered is that if you had polio when you were two years old, then around 30, 32, or 35, you start to experience this problem. If you had polio when you were 30 years old, it starts occurring around 60. We haven't really determined why, but it seems to be the fairly common factor.

Another school of thought that is being battled around, and I'm just going to throw it out for what it is worth, and I'm not here and neither are people working with us at the Institute, ready to call the shot on this, that in fact what has happened because of



the aging process, in those who had polio, is that their immunity system is beginning to break down. In fact, the polio virus itself might be acting up a bit. But that has not been confirmed in any way. The most common feeling is that in fact the whole problem is coming about because of premature aging process of those areas that have been affected.

In closing, let me say that as a result of the Symposium and our continued activity, we felt that there was a lot yet to be determined. We are committed to research, working not only at the Institute but throughout the world to emphasize to everyone that for some it is a problem and we recognize it. One of our first efforts is to get the medical profession throughout the country to recognize this. We are trying to get more physicians involved so that when someone who had polio comes in and starts talking about his problems, they will know what to do. We will be following this up with another Symposium. We think that activities like this to create awareness, to get feedback and get the medical community more involved, will lead to some more specific data later on, so that we may be able to deal with the problem in a more specific way.

I appreciate the opportunity to be here today and participate. I would like to thank all of those who have helped organize this whole thing and encourage you to continue to do more things like this because the only way we are really going to solve the problem is for everybody to get involved and to come out and say, "This is what I am experiencing." We can deal with it from there.

I would like to open my remarks by reiterating the thanks that I extended to the Roosevelt family when I visited Warm Springs about two weeks ago - thanks that they had given us in Canada the right to use the phrase "March of Dimes". We have been very lucky. We have been very successful. By using the March of Dimes method of raising funds, we have been able to help thousands and thousands of disabled people from coast to coast. It is a great pleasure again to thank Mr. Roosevelt and family for giving us that great gift.

I would also like to try to bring you up to date on how we function. In Canada we have an organization called the Canadian Rehabilitation Council for the Disabled - CRCDC. They coordinate the activities of each province. It is sometimes difficult to identify March of Dimes activities in each province. In Quebec it is called La Marche des Dix Sous, the Kinsmen Rehabilitation Foundation in British Columbia, and the Alberta Rehabilitation Foundation for the Disabled in Alberta. They all, however, use the logo "March of Dimes".

Our own organization is independent of the American organization. Indeed, some years ago, after the vaccine benefits became evident, we had a very heavy meeting with our medical advisors and we decided that though the American March of Dimes was going another route, we would continue to stay with physically disabled people, that the job was unfinished, and that, interestingly enough, no one quite knew what might occur to those people who were our constituents - the polio sufferers. It is now that (we appreciate) the wisdom of that medical advisory committee, that we can proudly say that we have stayed with our original concepts.

Our excitement about realizing that there was an emerging problem has resulted in our formally inaugurating a Post-Polio Program which is financially assisted by National Health and Welfare this fiscal year. The goals of the program are multiple and include developing a registry of persons with polio, networking among such individuals and forming groups and associations of people with such interests. Many of you here today are in those groups.

The Health Promotions Directorate Grant has enabled us to hire part-time staffing and to travel about in Ontario. But it does not go far enough in allowing us to pursue all of our goals. The initial grant is for \$25,000 this year, \$15,000 next year, and we require an additional \$75,000 if we are to achieve all that we hope to accomplish.

I'm delighted that we are hosts to our wonderful friends from Georgia. (It is) my feeling that the Georgia Warm Springs Foundation really is the spiritual home of rehabilitation. We hope to be able to work with them closely in the future.

## COMMUNICATION

Carl Spitzer

Let me just say a few words about Communication, which is my field. We all know that to be supported, a cause must be understood. It must be shared, and people must feel that they have a personal stake in its success. I've been so impressed with what I have read and heard here that I would be very timid indeed about trying to offer any counsel. Rather, I would be seeking counsel from you. The Advocate is a marvellous publication and I hope I can receive it regularly from this time forward.

Communication is absolutely essential to maintain news media interest and therefore to raise public awareness. Mr. Roosevelt spoke last evening about 40,000 children dying every day for lack of basic health care in other parts of the world and yet that goes almost unnoticed and largely unreported.

We have to increase communication to earn financial support, certainly, to encourage employers to recruit and train and promote persons with disability. We must communicate to form a global network or consortium among all the major health organizations, to immunize children at risk and to advance independent living for persons with disabilities of all kinds. The focus is local - in your own neighbourhood - and it is also global. We need to help each other. We can't be focused narrowly and expect to succeed. The problems around the world are enormous and they cry for our help.

At Warm Springs we are creating there an international training centre and conference centre and we hope that that will help us forge a permanent link and a working relationship with Ontario March of Dimes and the Roosevelt Warm Springs Institute for Rehabilitation for many, many years to come.

The goal that we share is maximum independence for persons with disabilities and eventually the eradication of preventable disability around the world.

I'm very pleased to be a part of this and to speak to the communication aspect of the program that we are all trying to forge in the total revitalization of Roosevelt Warm Springs. We hope that you will be a part of it too.



The beginning of the March of Dimes coming in full circle, you might say (in the sense they initially came into existence because of polio issues and are now having to look at them again) can probably be traced to 1980 when the NBC Network, in their program called "Primetime", had a program called something like "Whatever Happened to the 300,000 Polios?".

A number of polios interviewed on this program described increasing difficulties and distress at being abandoned and forgotten some 30 plus years or more after the onset of their disability. Following this program there were thousands of calls to the NBC Network and to the former U.S. hospitals where "polios" had once been treated. Although later difficulties had been increasing amongst "post-polios" for many years, this seemed to be the first media mention and the beginning of a resurgence of interest about polio issues some 30 years or more after the developed world had honestly believed that the devastation of polio had been wiped out once and for all.

Several international post-polio conferences in 1981, 1983 and 1985 followed, and "post-polios" came from all over the world to remind both themselves and others that polio issues have not gone away. Although the vaccine has protected people from the virus in those parts of the world that are fortunate enough to have access to it, the people who were once devastated by the virus still do exist and so do their problems. In fact, their problems are increasing as they get older and as important medical knowledge and interest has disappeared. The "post-polios" attending these conferences represented all professions and walks of life. They came using iron lungs, ventilators, braces and crutches. They went back to their countries, to their states and to their provinces determined to fight a new battle - the battle to increase public and medical awareness that "polios" still exist and do indeed have needs.

Several of us in Ontario were fortunate enough to go to these international gatherings supported by the March of Dimes in doing so. We listened, we watched, we shared with other ambitious, determined people, some of them literally plugged into the walls to breath. We felt incredible growing fellowship. In many ways we felt like war veterans. The battle scenes may have been in different geographic arenas for each of us but certainly the commonality of brotherhood that comes from being a "survivor" was there.

Those of us from Ontario came back to champion the cause of a group of disabled people that no longer had any special organization of its own, an issue which really bothered a lot of the polio people in this province. There are associations for Multiple Sclerosis, for Muscular Dystrophy, for Spina Bifida, andso on, in addition to

the March of Dimes, which is, of course, an umbrella support group for all of them. But there was no longer any specific identity for "polios".

The March of Dimes, which was of course, originally funded to deal with polio concerns, were fascinated and interested in this new polio phenomenon. They responded to these concerns and when I look back on the three and a half years since the first of these March of Dimes Polio Symposiums, I'm really quite surprised by what has been accomplished.

Almost immediately the equipment needs of "polios" who approached the March of Dimes around the province, were considered on a priority basis.

Our first provincial post-polio seminar was held in Toronto in April, 1983, and we have published proceedings from that which are still available. It's been fascinating to notice that the things "post-polios" want to talk about in Oakland, California or Alice Springs, Australia or New England, all seem to be the same. These are the areas you will see represented in the workshops of this afternoon. They deal with loss of function as you get older, the need to have to face using more equipment and more aids, and the tremendous psychological adjustment involved in giving up a level of independence and function you initially worked so hard to get. The other areas that keep coming up again and again are the lack of medical knowledge, the need for clinics, the need for people who know how to make braces like they used to and the need to do something about getting together with each other to discover other people in the world who share the same problems.

It's quite interesting, I think, from a socio-cultural point of view to realize that when "polios" came out of the hospitals 30 or more years ago, it was considered "not cool" to be disabled. If you were a "cripple" that was a bad thing. So everybody worked as hard as they could to get rid of braces and aids and visible signs and symbols which would indicate to the world they were disabled. They certainly didn't want to associate with any other "crip" who would make them feel that they were "one of those". So the long term consequences of the attitudes of that time have been that the "polios" have literally faded into the woodwork and been so disconnected with disability that they do not realize what support organizations, like the March of Dimes, or disabled consumer groups can offer. They often do not know others with similar disability and do not have personal support networks that could help tremendously.

Another area that we've accomplished much in is in communication through the media. There have been an increasing number of articles in widely circulated newspapers and magazines such as the Globe and Mail, Montreal Gazette, Maclean's Magazine, Newsweek, and in the rehab literature magazines like Caliper, Rehabilitation Digest (the CRCD journal), or the recent Advocate Supplement.

There have also been an increasing number of radio and television spots.

We've had meetings with medical people to discuss the issues and to encourage their involvement. It certainly pleases me that we have a number of medical people here today who are interested enough to come out on a Saturday, listen to what we have to say and hopefully pick up the ball and take it further.

We've developed a Post-Polio Registry. We've also developed a related Respiratory Registry, which includes all those who might use ventilators for whatever neuro-muscular reason, not just the polios. We now have over 1000 Ontarians on our Post-Polio Registry. We've had people inquiring from Nova Scotia to the Yukon Territories if they "couldn't please join our registry" even though they are out of the province.

We've had many inquiries about "post-polio" from other countries. Ministries of Health from other provinces and other provincial agencies have approached us to express their fascination with this renewed "post-polio" interest and to ask us to share with them everything that we have and do. We haven't developed the resources to be able to share our information as widely as we'd like to, but we're getting there.

We've also completed a research survey of the 1000 people registered so far. About 400 of you responded and have answered the questionnaire which was sent out to ask what kinds of problems you're having and what you feel needs to be done. Doug Rankmore, our research officer, will be giving you the results of this, this afternoon. Some of the data is very interesting but perhaps even more exciting is the fact that some Toronto lung doctors have looked at our preliminary data and said, "Hey, there are people here who've not indicated any respiratory problems, yet they're checking off things like dizziness, light-headedness, swelling ankles, etc. and these symptoms together could indicate respiratory failure problems". These physicians are interested in working with Doug further to look at this cluster of symptoms to see if there are people who might have respiratory sequelae that they really don't know about.

Polios in different areas of the province are starting to get together and develop regional groups. Ottawa was the first post-polio association to get started last summer and this winter the Toronto and Peel area have one as well.

A two-year grant from Health and Welfare Canada has also been received and this is certainly going to be helpful in enabling us to do more.

In conclusion, I'd like to say that Ontario's post-polios are probably no different than other post-polios, whether they may be in England, whether it's Europe, Australia, New Zealand, or the

United States. As a group, we've been described as the reason why many community support agencies, such as the March of Dimes, got started in the first place. We've been told that rehabilitation medicine as a specialty, is grateful to us polios because physiotherapists and physicians learned their treatment techniques from dealing with the wasted atrophied limbs of polio people. We've been told that polios are the reason why rehabilitation hospitals, separate from acute care general hospitals, came into being. We've learned that the anesthesiologists and those in respiratory medicine are grateful to us because the fundamentals of respiratory medicine and the science of ventilation was derived from the knowledge gained in ventilating thousands of people who were once in iron lungs. The medical profession has said many times and in many ways that they are grateful to us for teaching them all that they know.

Polios have also often been described as ambitious, attractive, independent and even downright demanding and aggressive in their efforts to mobilize people to get on with what needs to be done. Us "polios", who are, after all, pretty much like other people in the world, are now asking collectively not to be forgotten. Just as many years ago we were all individuals striving to fight our own individual paralysis, I think collectively we are now striving as a group to ask for needs to be met and not forgotten.

As chairman of the March of Dimes Post-Polio Committee, I was excited by the events of last night. I am excited about what we are going to accomplish today, by this "re-awakening of awareness" and by what we have to accomplish yet. I have heard a lot about the warmth and the caring and the respect of the people at Warm Springs for the polio people who go there. I've heard and sensed this, not just from our Warm Springs visitors today, but also from Ontario post-polio people who went there last winter.

In Canada we have the basic theoretical medical knowledge which could be readily built on. Put that together with that same warmth and caring, which is already present at the Aberhart Hospital's polio respiratory ward, and we'll have a Warm Springs here. By putting all our links together - as individuals who've had polio, as interested medical people, as individuals in the same community, within the regions of the province, with other provinces of Canada, and with the rest of the world, we're going to be able to do a lot to conquer polio. Not just through the development of more effective immunization practices throughout the Third World, but also by helping those who were once devastated by the disease. By being together and sharing like we are today, there is much we can do. I'm really happy to be a part of it.



I would like to begin this session by thanking everyone who responded to the survey questionnaire which was distributed to all members of the Post-Polio Registry. This type of endeavour and its accuracy are wholly dependent upon the participation of those involved. Without your cooperation we would be unable to say as much of what we presently know about the Late Effects of Polio, and the feelings of people affected by polio in early life. My heartfelt thanks is extended to all those who participated.

The Ontario March of Dimes Survey on the Late Effects of Polio was conducted through the summer and fall of 1984. A questionnaire was distributed to the 1000 members of the Ontario March of Dimes Post-Polio Registry.

The questionnaire attempted to gather data dealing with a variety of issues which, as identified through past research and through personal communications were thought to be relevant to the needs of Ontario's post-polios. Potential questions were generated from previous research and through input from the Post-Polio Co-ordinator and the Post-Polio Committee. The final format of the survey served to focus the investigation on three main areas of concern:

- 1) To what extent are Ontario's post-polios experiencing the late effects described in previous research.
- 2) What is their opinion of the existing services for them in Ontario.
- 3) What services do they feel are needed.

With these objectives in mind the survey was created and mailed and in the three months following, 416 responses (42%) were received. (The major findings of the survey were outlined and may be found in tables at the conclusion of this presentation.)

These findings support the results of similar research conducted in Manitoba, Georgia, Texas and Minnesota. Although differing somewhat in methodology and content, all studies to date dealing with the epidemiology of the Late Effects of Polio have resulted in mutually supportive findings.

In addition to the previous results, later analyses of the data have revealed other important findings. One such finding reveals that individuals experiencing new respiratory problems which they feel are attributable to the late effects of polio, experience other health problems with a greater frequency than those not experiencing new respiratory problems. Moreover, the "typical"

problems for those experiencing new respiratory problems are significantly different from the problems faced by those not experiencing new respiratory problems.

The results of this study have clearly shown the Ontario March of Dimes what work needs to be done in the immediate future. In response, particularly to the sections dealing with services, the Ontario March of Dimes has already begun to work toward dealing with the problems outlined. Present endeavours include an expansion of the Post-Polio Program through a grant from the Health Promotions Branch of the Federal Department of Health to fund a co-ordinator to assist in the formation of self-help groups around the province. Efforts are also underway to submit this study for publication to a Canadian medical journal. It is our hope this will increase the awareness of the Canadian medical community of the validity and extent of the new problems facing post-polios.

To address the clinical requirements of the problem the Ontario March of Dimes is currently seeking funds to create regional assessment clinics to diagnose and make suggestions for care of those experiencing late effects. The Ontario March of Dimes is also earmarking its 1985 medical research budget for studies dealing with the Late Effects of Polio. Additionally, I am currently involved in research with Dr. Monica Contreras and Dr. Roger Goldstein from West Park Hospital investigating the contribution of respiratory problems to other Late Effects of Polio.

In closing, I would like to say that I am heartened by the work that is underway to deal with the problems outlined by the survey. I have spent the last year reading the accounts of individuals who have been doubted and turned away by their friends, family and physicians. The time has long since come to appreciate, understand and act on these accounts and to address the problems outlined with real and concrete endeavours. Thanks once again to all who helped make the story clearer.

# Results summary — Ontario March of Dimes survey on late effects of polio

ITEM	FINDINGS
1. PEOPLE RESPONDING	416
2. SEX	Female - 61% Male - 39%
3. AGE	30 and below - 6 31 to 40 - 62 41 to 50 - 87 51 to 60 - 126 61 to 70 - 95 71 to 80 - 25 81 and above - 5 Average equals 54
4. EMPLOYMENT	Unemployed - 10% Retired - 21% Part-time - 9% Homemaker - 22% Full-time - 38%
5. CHANGE IN EMPLOYMENT STATUS	Decrease in Time - 37 Forced to terminate - 29 Early Retirement - 23 Decreased Physical Involvement - 17 No Job Mobility - 5 Other - 3 Total - 114
6. AGE AT ONSET OF POLIO	10 and below - 224 11 to 20 - 85 21 to 30 - 52 31 to 40 - 19 41 and above - 4 Average - 11
7. YEAR OF POLIO ONSET	1900 to 1910 - 5 1911 to 1920 - 16 1921 to 1930 - 58 1931 to 1940 - 62 1941 to 1950 - 112 1951 to 1960 - 134 1961 to present - 6
8. AGE AT MAXIMUM RECOVERY	Average - 17 years Youngest - 6 years Oldest - 84 years
9. CHANGE IN ARM USE SINCE ONSET:	Increase in use - 141 No Change - 253 Decrease in use - 35
SINCE MAXIMUM RECOVERY:	Increase in use - 10 No Change - 330 Decrease in use - 68
10. CHANGE IN LEG USE SINCE ONSET:	Increase in use - 208 No Change - 153 Decrease in use - 45
SINCE MAXIMUM RECOVERY:	Increase in use - 29 No Change - 271 Decrease in use - 105
11. CHANGE IN NUMBER OF RESPIRATORY AIDS SINCE ONSET:	Increase - 8 No Change - 367 Decrease - 41
SINCE MAXIMUM RECOVERY:	Increase - 11 No Change - 402 Decrease - 3
12. CHANGE IN NUMBER OF MOBILITY SINCE ONSET:	Increase - 95 No Change - 193 Decrease - 128
SINCE MAXIMUM RECOVERY:	Increase - 106 No Change - 262 Decrease - 48

## RECENT PROBLEMS ATTRIBUTED BY RESPONDENTS TO THE LATE EFFECTS OF POLIO

### MAGNITUDE OF PROBLEMS

With New Problems — 361/87%  
No New Problems — 55/13%

Health Problem	Number & Percent Indicating Problem	Average Age at Onset of New Problem	Average Years Since Onset of Polio
Muscle Weakness	268/64%	46	34
Fatigue	258/62%	45	33
Pain	213/51%	42	31
Changes in Posture	157/38%	42	30
Swelling	148/36%	44	32
Problems Sleeping	138/33%	45	34
Psychological Problems	130/31%	42	31
Headaches	116/28%	40	29
Respiratory Problems	111/27%	41	30
Dizziness	84/20%	44	34
Blackouts	47/11%	41	32
Total Health Problems	1671	43	32
Functional Problems			
Walking	216/52%	46	35
Climbing Stairs	196/47%	47	36
Lifting	143/34%	48	35
House Cleaning	137/33%	48	36
Decreased Social Life	106/26%	45	35
Problems Sitting	86/21%	47	36
Decreased Hand Use	79/19%	47	36
Bathing	75/18%	49	37
Elimination	73/18%	47	31
Dressing	61/15%	50	36
Food Preparation	57/14%	47	36
Sexual Functioning	57/14%	47	36
Problems Eating	53/13%	50	33
Pushing a Wheelchair	49/12%	50	38
Problems with Transfer	45/11%	52	37
Total Functional Problems	1531	48	36
All New Problems	3202	46	35

Average New Problems per person 8.9

### PROBLEMS WITH PRESENT SERVICES EXPERIENCED BY RESPONDENTS

1. Locating medical resources familiar with problems facing post-polios.	190/46%
2. No knowledge of what services are presently available..	154/37%
3. Locating suitable equipment.	113/27%
4. Knowing what services/equipment is most appropriate.	111/27%
5. Funding services/equipment needed	93/22%
6. Keeping equipment in working order.	57/14%

### NEW SERVICES MOST DESIRED BY RESPONDENTS

1. Collect and disseminate information on issues relevant to post-polios.	95/25%
2. Increase awareness of medical profession on problems facing post-polios.	92/24%
3. Development of strategies to deal with new health and functional problems.	73/19%
4. More financial support.	47/12%
5. Increased endeavors to improve access for the physically disabled.	33/9%
6. Establishment of peer support networks.	27/7%
7. Improvement of the image of post-polios and increased lobbying on their behalf.	19/5%

## CURRENT CONCEPTS IN ETIOLOGY INVESTIGATION

### AND TREATMENT IN POST-POLIO

Dr. Rubin Feldman

What I plan to do today is to take you on a trip through various aspects of this very interesting and fascinating disease. I'll be using Late Effects of Poliomyelitis and Post-Polio Syndrome as being synonymous and I'll be leaving PPMA, the so-called Post-Polio Progressive Muscular Atrophy to discuss a very particular group of situations that exists in some individuals who have this problem.

I suppose historically, this problem dates back to the day that any one of you had poliomyelitis, certainly 20 or 35 years ago, when you were initially afflicted by this problem. As a result of this you had rather severe paralysis, depending on the situation and depending on the person, and then some recovery. Everything went well until individuals who had poliomyelitis began to notice some symptoms that were rather disheartening.

For the past eight years, I have had the privilege of being asked advice regarding muscle weakness, fatigue, muscle and joint pain, which we identified early as being quite a bit worse in individuals who also had respiratory polio initially.

As any good, proper-thinking physiatrist, I put them all on physiotherapy and tried to get as much benefit as possible out of strengthening exercises as classically performed in physiotherapy. To my consternation, I noted that some people did very poorly while some people did very well. So, when one sees this, one begins to ask the question: "What is it that is happening, that should make that difference when physiotherapy is being given?"

Fortunately, over the past three years or so, there has been some additional information through the literature and throughout other sources, which first identified clinically that, if one gives intense exercise and fatigues muscles that have initially been hit by poliomyelitis, those muscles are going to disappear. They are going to get worse. They are going to get weaker and ultimately, their volume will be reduced drastically.

The information has also given us some insight into the respiratory difficulties and why they are worse. I guess the best example I can give of that is a patient of mine whom I had first met in the intensive care unit at University of Alberta Hospital. I had met her previously socially because we were on the same rehabilitation committee. She had respiratory polio and also had a very good physiotherapist. When she began to notice some difficulty with her respiration, she went to the therapist and the therapist again classically said, "Well, let's give you some breathing exercises, dear, and you'll do very well, indeed."

This is the way you go about doing it." He gave her an inspirometer which gave her some resistance against diaphragmatic movement. Three days later she was in the intensive care unit unable to breath. This, I think, graphically pointed out to us that, in fact, one must not over-fatigue, or even fatigue, these muscles, because they will deteriorate in their function.

You have heard an excellent presentation just before mine about the epidemiology as it relates to Ontario and there have been some other very good studies done which indicate, as you have heard, that between 20 and 30 percent of the previous patients who had polio may get these symptoms again and will get Late Effects of Poliomyelitis.

Of great importance have been some of the investigations that have been done and, in particular, what is known as Single Fibre EMG - Single Fibre Electromyography, which, among other things, identifies changes in muscle as a result of some changes that take place to the innervation of this muscle. When the studies by Drs. Wiechers and Stahlberg were done, they were able to differentiate between the changes known to be caused by aging of this junction, and problems related to Post-Polio Syndrome. In addition, we were able to differentiate between the usual "population" of Post-Polio Syndrome and a special group, fortunately very small, in which rapid deterioration takes place. I have seen two such patients. We don't know why this happens, but no matter what we tried to do - one of these patients was respiratory and the other one wasn't - over three, four, maybe six, seven months, there is a rapid deterioration of function and there is no recovery.

So these things have come through to the point where last year in May there was the Warm Springs Medical Symposium. I was privileged to be invited to that. We had a tremendously good interchange of ideas. We were able, I think, to identify what PPMA really is or what it is thought to be.

I presented a paper there on how we in Canada are able to treat patients in relation to hospitalization without bankrupting them, as would happen south of the border, and identify that it is really quite necessary to continue treating patients in a way which I will describe shortly, for a long, extended period of time getting our ego trips out of small improvements over time. When this was described, some people in the audience at the Symposium said, "You're talking about something entirely different, because what we're finding is we're giving our patients physiotherapy, and they're getting worse."

When Dr. Owen of Minneapolis found similar findings because he had a funded program that permitted him to do similar work to what was being done in Canada, they began to take a second look at this and began to realize that if an individual is told to go home and do physio - if a little bit is good, a lot is better. I've just said



that a lot is not better in polio. So they deteriorated instead of getting better and they were back to square one, or maybe square a half.

We were able to identify at the Symposium that, in fact, there is the need for extended physiotherapy contact with the requirement for patients, by patients, and patients by physios, etcetera, and that if one does this there are possibilities of further improvement.

Besides that, there was the formation of an international research task force which is a very exciting concept. It resulted in frequent telephoning between Dr. Owen, myself, Dr. Joe Kaufert in Winnipeg and others. We are hoping that this task force, this network, could be expanded, preferably across this country with similar types of information flowing through because of similar work being done. We would then be able to see enough patients to really see a trend and perhaps identify something which we can deal with.

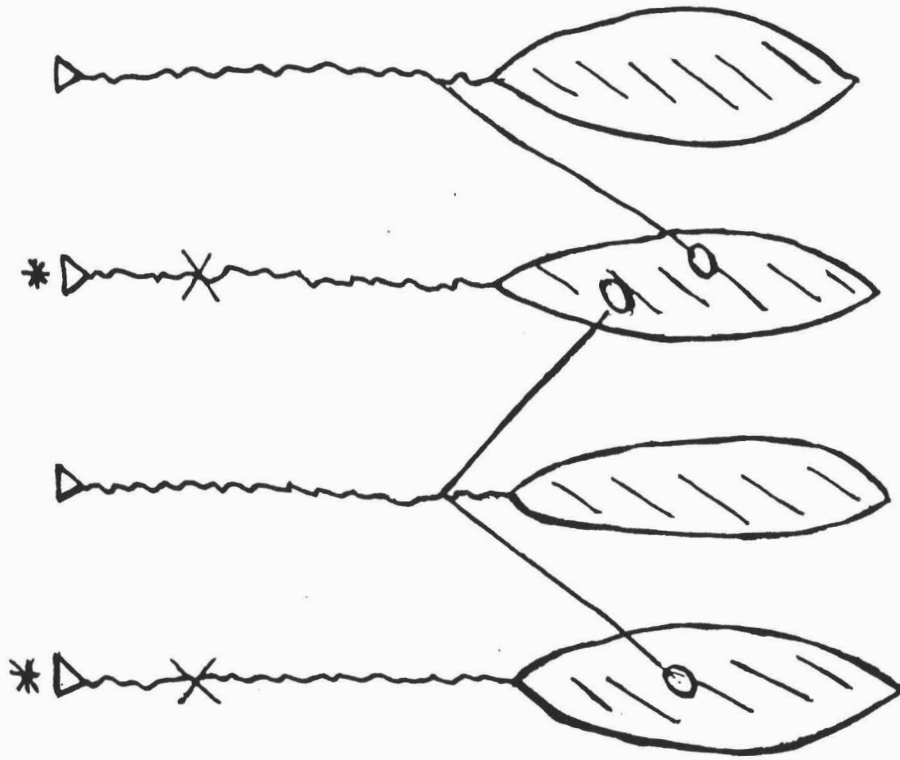
This brings us to the present time, where I think we can say with some degree of certainty that we have a pretty decent idea as to what the mechanism (of deterioration) is, and we are becoming aware of methods of investigation of Post-Polio Syndrome which then guide us as to how to treat it. So what is the Post-Polio Syndrome?

I will now present a slide which identifies for you diagrammatically what we can look at when we are dealing with the motor neuromuscular system. The triangle on top will correspond to the anterior horn cell. The squiggle in the middle means that there are a number of feet distance from the anterior horn cell. It identifies for you that it is a continuous system which is longer than one would think. The red masses of which there are four, identify four adjacent muscle groups. The inverted V at each of the muscle groups is indicative of the neuro muscular junction - the junction between the nerve going down to the particular muscle group or muscle to which it is going. This is normal. Finally, we have asterisks. Numbers one and three are the ones where all the action is going to take place.

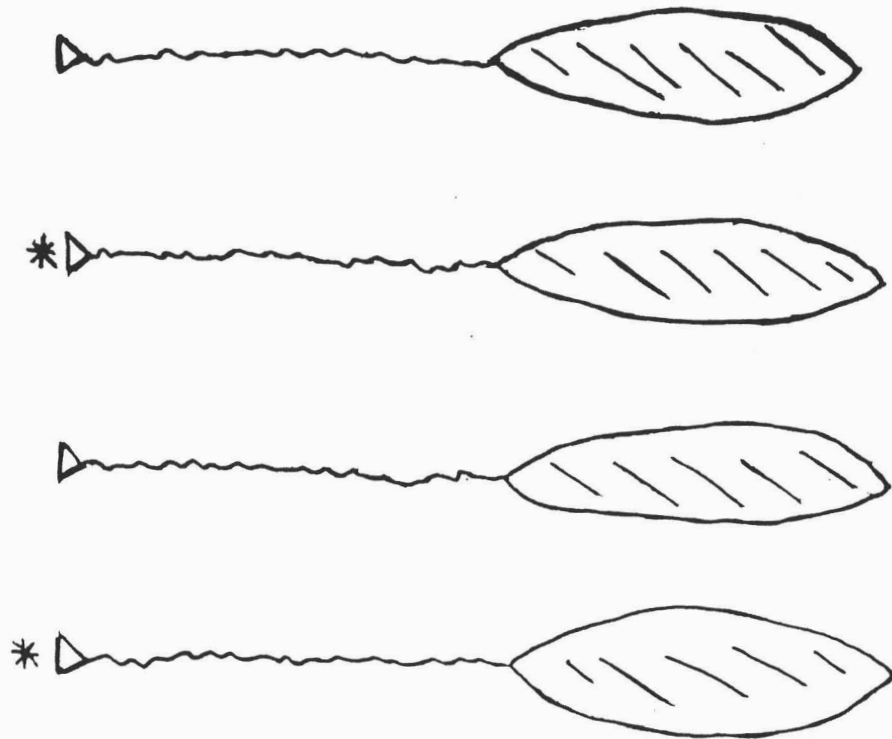
In the next slide we can see where the action is. Numbers one and three are the anterior horn cells in which the virus occurred, causing death of that anterior horn cell. The muscle system is no longer functioning in those particular areas. As a result, in acute onset of poliomyelitis, there is lack of function of muscle groups one and three. The X indicates that those are the two muscle systems that are no longer functioning.

When you experienced recovery what was actually happening was that a sprout was being formed to the existing, but not functioning,

SLIDE II



SLIDE I



muscle group from the existing, but functioning, nerve fibres, as you can see - from the functioning nerve to the muscles whose anterior horn cells had been destroyed by the virus.

For 20 or 30 years this system worked very well. There is good function created in the muscle that has now been re-innervated. Then after 30 years something happens. Where it happens, appears to be on the inside of where I put these black circles. What Dave Wiechers notes as being so-called metabolic fatigue takes place. As a result of that, putting it very simplistically, the messages just don't get through the neuromuscular junction to the muscle. As a result, weakness occurs and further, if one attempts to force the system, one cannot force the system, because there is less function in the neuromuscular junction. Trying to force it only makes things worse and the muscle begins to deteriorate accordingly. That is, if we try to force it - if we try to cause fatigue. It is simplistic. It is the explanation which is currently guiding us. As I said, I use my blackboard in my office to do this whenever I see a patient, just so as to give them and you, I hope, some visual feel for what is actually happening - what has happened over the years.

So then, Post-Polio Syndrome turns out to be a process in which, after re-innervation had taken place, there is neuromuscular transmission fatigue, metabolic fatigue. This then corresponds with the changes that have been found on Single Fibre EMG, as they relate to the findings.

What are the main symptoms? You have heard them before and I'll repeat them again because there are a couple of other things which we seem to be finding, not quite routinely, but frequently enough to make it all worthwhile talking about.

The weakness - particularly in muscles that have been weakened previously by polio and then recovered, but other muscles as well. I think that is very important because as we'll see later when we talk about pain, the fact that other muscles also become weakened, identifies for us the types of approaches to treatment that we have to do.

It is not unusual to find this weakness resulting after a person has had a totally unrelated incident, such as abdominal surgery, a motor accident, a fall, pneumonia, or any kind of immobilization in which they had to be in bed for any length of time - totally unrelated to the fact that they had poliomyelitis. They find that after that, they have difficulty getting themselves going again. While we know that this will happen with immobility, for example, if we put a cast on a person's leg because they have had a fracture, this is also happening. The recovery rate is just not there. Instead of recovering as we would hope, the situation continues to become worse, and individuals continue to lose function. It can happen after stressful situations, such as a death in the family or a divorce.

Secondly, there is a general decrease in function whether it be function in ambulation, i.e., in walking. We note a deterioration in distance walking, but also in the quality of the walking. An individual who could walk four or five miles at a time - a real hiker - now finds himself limited to one city block. It is a definable change in the distance a person can walk and instead of doing that without any ambulation aids, he now might require two canes. So the quality of ambulation is impaired as well. To this is added the problem of self-care. "I can't put my jacket on properly, I can't put my sweater up over my head any more and bring it back down again. I have difficulty in getting out of my chair and standing up. I need a pillow now that I didn't need before."

Thirdly, this idea of generalized fatigue of muscle. This is a physical thing. People actually feel this fatigue, they're exhausted. They just cannot do another contraction of a muscle group. I think it is related a lot to the emotional frustration that Audrey King talked about - the idea that when they try to get help, they have difficulty, and added to all of these things, the additional problems of falling, and sometimes fractures that result. So that you have a complex of a change of function as a result of this weakness and fatigue.

To this is added in some people, not in all, the problem of pain. I really must, at this point, emphasize, and almost over-emphasize, that just because you had polio does not mean that you cannot have any of the so-called over-use syndromes common in our civilization. You can have the over-use syndromes, such as bursitis, capsulitis and tendonitis. Perhaps tendonitis is something which is more common, particularly in individuals who need to use canes or wheelchairs. The joint pain as a result of weakness or overlying muscles, where the support of that joint no longer is what it should be, will also result in some difficulties. Then, there is primary muscle pain for which, I'm afraid, at this point we really don't have the answer. When I mention that it is severe and can be disabling - it is certainly both of those. The muscular pain will very frequently be increased as fatigue is increased.

So there are two signals that individuals should be looking for when doing exercise. One is the fatigue, and the second is the pain - articular joint pain, common as I have mentioned. Rarely is it radicular. In other words, it is not the travelling type of pain that one gets when a nerve is, as one says, pinched in the neck or in the back, resulting in pain going down the leg or arm. Not to say that it can't happen, but we are dealing then with the different type of discogenic type of pain which is radicular pain and not the type of pain we are talking about in the Post-Polio Syndrome. When I say it is causalgic, I don't know how to spell "Yuck", but that is the kind of thing it is. It is a burning, terrible type of pain. And it's a very difficult problem.

This so-called neurogenic pain, associated with the muscle fatigue, is the one we don't have the answers for. I wish we did. We have tried various types of medication, sometimes, anti-inflammatory, but more than likely, the kind which one wishes to use, for example, in seizure disorders. That is not to say that this is a seizure disorder. But we do find, as we do in amputees, that at times when you have this kind of phantom pain in amputees, again a causalgic type of pain, that there are some medications that by coincidence are being used also in seizure disorders that sometimes can be helpful, and are worthwhile trying.

Individuals who had respiratory difficulties before, may very well have them again. They do cause a great deal of difficulty. Not only that, but they reduce the opportunity to be able to respond appropriately to physiotherapy, mainly because the oxygen supply is reduced as a result of these difficulties. There are other symptoms which can be related and the respirologists in the audience, I am sure, can add more which can be related to respiratory difficulties. Dr. Neil Brown, our respirologist with whom I work, talks a lot about the difficulty with morning confusion, with headaches, the sleeplessness that some people have, and finds that with assisted ventilation at night they have lesser difficulties during the daytime and can carry on a more appropriate existence in the daytime.

What about the investigations? With the impetus created by the findings of Dave Wiechers and Dr. Stahlberg in Sweden on what happens in Single Fibre EMG, was some mention in the literature about changes in neuromuscular transmission.

We decided to try some EMG studies to see whether, in fact, we could find differences which perhaps could be peculiar to this problem. In fact, we do find that on what we call needle electromyography - that is a process in which a needle is inserted into the muscle quite painlessly - you identify firstly, what happens when the needle travels through the muscle. Secondly, you identify what happens when the needle is addressed inside the muscle. Thirdly, you identify what happens when you ask the person to move the muscle in which there is a needle. The needle is actually a teflon-coated wire only denuded at the very end. So it is like putting your eye into the middle of a muscle, looking around and saying, "Hm, this has some nice electricity."

When we do this, we find that there is, in fact, a decrease and sometimes a total absence of what we call insertion activity. That is the rumble that we get as a needle goes into the muscle and as it is travelling through the muscle. We don't find this in any other illness that I know of, except in muscles that are totally dead or fibrotic - in other words, very hardened - so that they are really not functioning as muscles any more. Despite that, if we then hold the needle in place and ask the patient to move that muscle, lo and behold, we'll find what we call motiutive potentials firing. So, it is not a dead muscle. It is a muscle



which is still functioning, but acting as a dead muscle when we insert the needle. The motiutive potentials, which is a way of describing what we see on a screen when we ask a person to move that muscle, appear to be normal. We sometimes note that there are some polyphasic potentials as would be identified in any kind of anterior horn cell disease, and occasional fasciculation. These are findings that we'll see in muscles that we have identified as being weakened and are possibly weakened as a result of polio problems, that is, Post-Polio Syndrome.

In other muscle groups which would not be affected by this, but are weakened, we will find normal insertional activities, no polyphasic potentials, normal motiutive potentials, but there will be a decreased number of them corresponding to the weakness that has happened.

The second thing now takes us back to that old neuromuscular junction that I referred to before. We find that there is what I call a distortion of neuromuscular transmission and, just as we do when we are testing for something known as myasthenia gravis, there is a decrease or a decrement in the response to repetitive stimulation. The interesting thing is that there are times when there can be an increment and in the same muscle, and in the same neuromuscular junction, so there is truly a distortion. There is a difference each time you try to stimulate in groups of five, the neuromuscular junction. You get differences in the response each time. Again, very peculiar to this type of problem.

This then permits us to try to differentiate between those muscles that have been identified as being weakened as a result of Post-Polio Syndrome and those that would be weakened as a result of disuse. Be the latter term I mean that if you have pain in your shoulder, you'll have a tendency not to want to move that shoulder. You are paying a price. You might get a frozen shoulder as a result, but the point is that if you are not using the muscles around the shoulder, those muscles are going to become weaker. They can lose strength as well as substance, but they will have normally empty findings. If an adjacent muscle to one that has been affected by polio is not functioning because of this, you will have adjacent one to the other, for example, biceps that is normal and a deltoid muscle affected originally by poliomyelitis, having these changes in EMG. This permits us now to differentiate between these two different kinds.

What about the treatment protocol? What do we try to do? Before dealing with that, I must emphasize that it is absolutely imperative that a diagnosis be made as to what is going on. Just because 20 to 30 percent of people who had polio now have Post-Polio Syndrome, does not mean that everybody has Post-Polio Syndrome. Of that population, 70 to 80 percent will not have it. One has to consider that as a distinct possibility. I had a patient in just last Tuesday who was convinced that he had it and his muscles were stronger than mine. Truly, he did not identify clinically any

evidence that he had Post-Polio Syndrome.

The second thing is that it is important to have a differential diagnosis made for problems related to weakness. Just because a person had poliomyelitis doesn't mean that he can't have whatever else you find in the medical books causing weakness, causing pain, causing fatigue. So when we talk about the treatment protocol, we are assuming that the differential has been ruled out and that what we are left with, is a person who truly has clinically and electrophysiologically evidence to indicate the presence of Post-Polio Syndrome.

Classical physiotherapy tells us if you want to strengthen a muscle, as I said before, "Beat it to heck." Give it as much strengthening as you can and when you do that, and even if you go to anaerobic activity, that is activity in which a relatively reduced amount of oxygen is used, you will improve that muscle. Not so with Post-Polio Syndrome. So we talk about non-fatiguing, strengthening, progressive, resistive exercises.

What we do, basically is identify with the patient, very particular to that patient, the amount of weight that that individual can lift, depending on the portion of the limb we are dealing with, and the number of repetitions of this lifting that can be done. Let us assume for a moment that a person is able to flex his elbow and with a five-pound weight in his hand, he can do it 20 times, after which he tells you, "I am fatigued. I really can't carry on." We then start with, say, instead of ten repetitions, five repetitions of these five pounds. Very gradually, over a period of time, always avoiding fatigue, we get to the point where those five pounds are lifted 30 times. At that point, we increase the weight maybe to eight pounds, getting back again to ten, maybe less repetitions, gradually working it up to 30 again and then increase the weight, etc. We carry on that way until we get to the point where the patient tells us, "That's it. I really can't go any further. Any additional is causing me fatigue." And we stop and that's the end point. That is the point at which any further physiotherapy will cause trouble. It is a long term program. It is slow progress, but done in this way with careful attention to these details, things seem to work out.

The second thing we do is give a generalized exercises program. This is something that Dick Owen in Minneapolis has been doing a lot of very successfully. Conditioning, and incorporating into that conditioning program the physiotherapy done classically on those muscles that are weakened as a result of disuse. Those muscle groups that are not affected by Post-Polio but which are weakened, can be treated as you would any other muscle.

Thirdly, we have inserts placed into the floors of our unit identifying five-metre distances. We have patients walking up and down a corridor using whatever ambulation they may require and again, the same method: identifying the distance before they get

fatigue and using that as the starting point to gradually increase.

Occupational therapy is required not only to attempt to improve function in these patients, but also to adapt their function so that whatever they are doing and whatever constitutes as their lifestyle, they should be able to continue to do, but more effectively and more efficiently, given the disability that they have.

Finally, a change in orthotic management - the braces. Those metal and leather clunky braces weighing ten pounds each that Roosevelt had will be replaced now by polypropylene braces that fit into the shoe and may or may not have metal knee joints. These weigh decidedly less.

So you see then a combined effort of a multi-disciplinary professional team consisting not only of a physician, but physiotherapists, occupational therapists, social workers, psychologists, rehab nurse. It is classical. The team approach to this is what is so terribly important.

We have three choices in the way in which this is handled. I am fortunate in having the opportunity of being able to get patients into the hospital when I have to. If I find a patient is really quite weak and either lives far from the hospital or really would be tuckered out by the time they arrive in physiotherapy, I'll bring them in as an in-patient. I feel totally justified in doing that. They will get physiotherapy twice a day and they will have rest periods in between, in bed. So they have the opportunity of resting and still benefitting from the therapy.

My second choice is bringing them into a hostel which is associated with our hospital. They can have a spouse or significant other, as they call them, living with them. They enter into the hostel for whatever period of time they require. We have them closely contacted with physiotherapy twice a day, once again.

The third way, for a patient who isn't too badly off, would be as an out-patient.

The results. We find that we are able to strengthen these muscles. They demonstrate the strengthening effect on muscle testing. I'll show you how that is all done in a moment. There are limitations, of course, and I mentioned it when I was talking about this. The limitation is the patient telling us, "That's it." Before they ever start the program, we point out to them, "There will be a point when you are going to have to tell us honestly and without trying to push the system, 'That's it. I can't go any further.'" If they don't do that, we won't know, and if we don't know, they will get worse.

Those are the limitations that we impose on the whole thing. With the help of occupational therapy and the improvement in

muscle function, we are able to improve the general function. We are able to improve the efficiency as well, by using appropriate time-saving and energy-saving methods. The falls become less frequent and finally disappear. Ambulation appears to improve. This is not to say that they may not need ambulation aids, but we have found that individuals who have recently gone into a wheelchair, can get out of it again because of this. Perhaps an individual who had two canes in the beginning, now needs just one, and interestingly, a person who might have required a long leg brace, now with improvement in quadriceps function, for example, only needs a short leg brace because the ankle is still unstable. So there is improvement all the way along over time.

I have a table describing the events of a person's life who came to me about 18 months ago. Look at 1 as being a barely discernable muscle contraction, 5 as being unbreakable muscle contraction - just can't resist it - and 3 as being the ability to move the limb through one range of motion against gravity. You can see under December '84, what this person was able to do in a particular muscle. We saw her as shown here in February '84, March '84 and April '84. You can see how progress took place from the initial onset of treatment until that time.

This is, unfortunately, a method of measurement which is very subjective. All I can say is that I was the only one who did them and so there wasn't, at least, the problem of two people measuring and getting different results. If anything, when I do this, I make an attempt to minimize the improvement rather than to maximize it, to make sure that we are not going into that kind of error.

We have thought about going on to the Sybex machine and trying to determine strength and torque and so on, that way, but we find that very tiring for the individual and we are not yet sure whether Sybex would be a proper way of measuring these muscle changes.

However, concomitant with achievement at the middle of 1984, was an additional improvement in that, instead of falling twice a day, she no longer falls. Instead of telling the family to go on hiking without her, she now goes on shorter hikes with them. She has become an active member of her community group which she initially had to give up, and now does kitchen activities which her husband had started to do. So that, in addition to improvement in muscle function which we can identify perhaps crudely on measurement, there are other additional things which have helped (substantiate the measurement).

It is all well and good to say that you can treat a patient for six months and they are going to improve. What happens in the long term? We saw this patient on sixth month follow-up just a short time ago, and this again is a crude method of identifying for you what happened. The different colours (on this slide)

correspond to the different activities mentioned in the previous table. The exciting thing about all of this, I think, is that the straight line arrows that you see along here, demonstrate that with a properly organized and managed maintenance program and a patient who is really interested in making sure that she stays better and has it all together very nicely - and those are a lot of ifs - but given those, six months later this individual has had no change at all in muscle function, so that it looks as if there can be a carry-over. I don't know for how long. I have no idea. I do know that for six months there is a carry-over.

The methods which we use, then, to do all of this, start off with a questionnaire - the almighty questionnaire - which gives us information not only as to the initial polio but also changes that have taken place. I do go into some details about the kind of aculation aids that are required, that were required before, and so on.

Complete evaluation. It is essential, once again I mention it, that we make sure that what we are dealing with is what we are talking about. Otherwise, we are doomed to all sorts of terrible things. Once that decision is made, treatment is done as I described, either as an in-patient, or an out-patient, or a hostel patient. We schedule monthly reviews to see whether there is long-term gain. We feel that the prognosis is really quite good in most of these patients.

I mentioned before that there were two patients who unfortunately did very poorly. I think that that is really what we are dealing with when we talk about PPMA - the Post-Polio Progressive Muscular Atrophy. The question of whether PPMA exists more than that, would maybe have to do, as I mentioned before, with the results of a different method of approach towards treatment.

What does the future hold? I think the future bodes well if we are able to continue doing this, but I must say that besides emphasizing the correct diagnosis, besides emphasizing that one should realize that only 20 to 20 percent as far as we know now, of that post-polio population will get this, which means that 70 to 80 percent won't, there is really a need for more data, for more information. If we can bring that to bear on something like what we are doing here today, by influencing individuals across the country, then we'll really come up with the proper answer.

I would hope that the symposium here today will have as one of its goals, interesting individuals who are physicians, who can undertake a clinic and a multi-disciplinary program for these patients.

That's as it stands, as we see it now. It's an exciting concept. We are not seeing nearly enough individuals. I would like to see more because there are more that are being asked to be seen and strongly suggest that if physicians are interested in starting a clinic and treatment program, if they mention it in the right

quarters, that they are interested, there won't be a lack of patients, unfortunately.



Facilitator - David Logan  
Recorder - Douglas Rankmore

The participants of the Workshop represented a broad spectrum of concerns. Approximately half were post-polio participants and the remainder, rehabilitation professionals representing a variety of disciplines, including general practitioners, respiratory physicians, occupational therapists, physiotherapists, orthotists, researchers, and equipment suppliers.

Initial discussions centred around the possibility that many of the new problems being faced by post-polios may have an origin in respiratory problems even though it may not be apparent to individuals that they are experiencing any obvious respiratory difficulties. Dr. Monica Contreras explained that the neuromuscular fatigue that has been discussed as a source of problems such as muscle weakness and general fatigue may actually be only the first step in the cause of such problems. It is thought that the muscles controlling breathing experience premature fatigue, causing the lungs to draw less breath (particularly during sleep). The lack of adequate respiration causes higher levels of carbon dioxide and lower levels of oxygen in the blood. Over a prolonged period of time this has the effect of lessening one's desire to draw a satisfying breath and may be responsible for swelling problems, sleeping problems, blackouts, headaches, fatigue and muscle weakness.

Further discussion revealed that several members of the Workshop had experienced these symptoms as well as obvious respiratory problems. One participant explained how respiratory therapy alleviated his symptoms even though he experienced no 'obvious' problems breathing. Participants experiencing any of the listed problems were urged to consult their physician or Dr. Contreras at West Park Hospital for a comprehensive respiratory assessment.

The discussion then led to issues of respiratory therapy and equipment. The characteristics of both positive and negative pressure ventilators were discussed as well as the potential for improvement of equipment using new technologies. Representatives of Life Care were present to explain equipment previously unavailable in Canada that is now for sale within the country. They also outlined that they are now in a position to support all equipment they currently sell in Canada, instead of in the United States.

The discussion closed by outlining the problems post-polios felt were of the highest priority. Participants outlined the need for increased awareness of emergency techniques such as frog

breathing, and the need for increased research into the real cause of new problems faced by post-polios. Participants also stated a desire for the establishment of a comprehensive assessment scheme in Ontario similar to that currently in use at the Roosevelt Warm Springs Rehabilitation Foundation.

Finally, participants were informed of recent efforts by the Ontario March of Dimes and others toward the provision of more comprehensive services for post-polios, including a research project currently underway between the Ontario March of Dimes and West Park Hospital to investigate the contribution of respiratory problems to Late Effects of Polio, and a proposal for the establishment of regional clinics to assess Late Effects.

Facilitator - Judy Bowles  
Recorder - George Glover

The proceedings of the Workshop can be summarized under four headings:

- 1) What information do post-polios need?
- 2) What information should be shared with doctors?
- 3) With whom should information be shared?
- 4) What mechanisms can be used to share information?

1) What information do post-polios need?

It would appear that post-polios need information on what doctors are knowledgeable about the syndrome, what medical facilities specialize in diagnosis and treatment as well as other pertinent information such as reasonable living accommodation which is near to medical facilities for those people who have to travel. Another topic about which there was significant discussion was the whole issue about exercise. Many post-polios are unsure what exercises to use, how often they should exercise, and how vigorously they should exercise. The basic question that is in the back of nearly everyone's mind is: "Do I have post-polio syndrome?"

The final item of information that it was apparent that post-polio people need is their own medical records. It is possible to obtain records from institutions where one has been served, and it was also suggested that in the future post-polios should keep their own records which would include - date of doctor's visits, medication prescribed, dosage prescribed, exercises recommended and any other treatments or tests that are used in the course of the diagnosis.

2) What information should be shared with doctors?

It became apparent that it is important for post-polios to share their own personal medical history with their current doctor. This relates back to the requirement that post-polios have to obtain as full a set of their medical records as possible. Secondly, because many doctors do not have access to the research and the literature regarding post-polio syndrome, where possible, information about post-polio syndrome should be shared with one's own doctor; this would include books that are available on the

topic as well as current research such as the survey that was recently published in The Advocate.

3) With whom should information be shared?

It is important that post-polios share information with one another in order to gain what insight they can and to provide each other with mutual support. However, in regard to the medical community it is also important to share information with general practitioners with whom one has contact, and where appropriate, with specialists who have an interest in the area of post-polio syndrome, or who because of their specialization may have a particular contribution to make.

4) What mechanisms should be used for information sharing?

It became apparent that those present at the Workshop saw the Post-Polio Association as an important mechanism for sharing information among themselves which could be further shared with the medical community. A mailing list is available through the Post-Polio Association, and newsletters and other information are mailed out to the members of the association from time to time. This is a very important vehicle for sharing new and pertinent information regarding post-polio syndrome. Several people also mentioned The Advocate as a valuable mechanism for sharing information among post-polio members, and also for getting information to the medical community regarding the post-polio syndrome. One of the doctors present suggested that efforts be made to contact the Ontario Medical Association and get from them a list of doctors who are interested in the whole area of post-polio and who would be prepared to have their names published so that those people who are in the Association and other people in the medical community might become aware of the interest that particular doctors have, in the whole area of post-polio. The final point that was made in regard to sharing information was that because of the fact that people in the Post-Polio Association come from different communities across the province, it is important to know what resources are available in the various geographic areas and that some sort of compilation be made of resources available by geographic area, and that this list be circulated by means of the association mailing list or The Advocate.

### Workshop #3

### Support Group Development - How to Network

Facilitator - Roberta McEachern  
Recorder - Jane Szilvassy

The facilitator led the discussion by outlining her own experience in setting up a post-polio support group in Peel. She had found it useful to look at the March of Dimes structure as a whole to establish where a support group would fit in. The Peel Advisory Committee then set up a Post-Polio Sub-Committee which would have two functions: networking and support groups.

She outlined two types of support groups: one made up of individuals with common goals who meet together at events which may be social, with invited speakers and open to anyone, the other, would be by invitation only to the target group. This group would start small and its goal would be to provide guidance, support and assistance.

There was a great deal of discussion on the subject of a small, seemingly exclusive group versus the type of group recently developed in Ottawa. The representative from Ottawa said that their experience showed it was possible to accomplish the goals of both of the above groups through one large group. At their meetings, half of the meeting might be taken up by a speaker and half by interaction between individuals, thus providing the support and mutual assistance.

Although the facilitator stressed that her group was indeed small (four members) they had only just formed. The general opinion of the Workshop participants was that this method excluded many people who needed help. Some participants likened the Peel group to a psychological-type group and everyone agreed that this was not what they were looking for. The main interest was in networking and getting recognition of the existence of the post-polio problem.

Facilitator - Jane Staub  
Recorder - Andria Spindel

In identifying the major psychological issue for people who are experiencing what has become known as the "Post-Polio Syndrome", Fear was identified as a major feeling, and it is fear that post-polio will be perceived by the individual as a psychological issue, (not a medical one), and even more that it is. a psychological issue.

The group identified a series of issues which are summarized here conceptually:

Families fear for the individual who has symptoms that they are now at great risk and perhaps may even die; individuals' own fear that they are experiencing polio once again; and resistance in the individual to let others assist in doing normal everyday things, while resisting pressure on the individual to give up, to rest, to let others do for him or her. Feeling guilty for not being able to do the things that one once did, yet perhaps in some instances resenting others who are expecting one to continue to do things in the old manner; an increased isolation as friends exclude one from normal activities recognizing that physical fatigue hinders the individual from participating, isolation even induced by oneself in having to opt out of activities so that one does not hold others back in their pace. A change in oneself's image through the altering of health status; and resentment around those people who think that the individual might be contagious and are even frightened by them. Concern about the lack of services or identification of experienced post-polio individuals and the lack of medical support.

Some of the psychological issues were not negative, for example:

Some individuals pointed out that families providing assistance and encouraging one to rest might be a very positive supportive thing to do, contributing to the saving of energy from daily tasks to allow for more participating in more important events; several people found that friends were definitely supportive and were willing to find compromises in the activities in which they shared with their post-polio friends; the increasing media attention on phenomena had been noticed; and every consideration that one can find others in similar situations and be mutually supportive would seem to be something of a current experience and an increasing need.

There were suggestions in the group as to how to cope with psychological changes accompanying post-polio, the fear of it being only a psychological issue itself in fact impacts on one's



well being. Some of the suggestions included:

Accepting realistically one's capabilities about what one can do. It is suggested that people maintain humour, develop a close relationship with one's spouse or a friend that someone can speak to about one's feelings, participate in discussion groups and get involvement of friends and family to better understand what the individual himself or herself is experiencing. Learn to say "no" so that one does not go beyond one's energy or ability, and support institutional studies and research into the phenomenon. Some people described their own personal experiences to their adjustment, such as a daily recreation program, reduction of full-time work, reading more on the phenomenon and becoming familiar with it, and becoming familiar with some of the services and social programs available for people who have disabilities.

The major approach was practical in the group, and this recorder sensed that the major common concern was addressed and that more discussion groups, probably within the local community, would go a long way to alleviating the issues deemed to be psychological.

**Workshop #5**

**Assistive Devices - Availability and Funding**

Facilitator - Linda Lyons  
Recorder - Alison Walton

Twenty-four people attended the Assistive Devices Workshop. There was complete consensus that a very great need exists for a comprehensive information panel on assistive devices and associated services. The information and ideas documented below were shared at the Workshop.

- 1) Ontario Ministry of Health Assistive Devices Program. For information call 1-800-268-6021 (Community Health Programs Branch).

The adult program may start this fall (1985). OHIP coverage will be 75%. Not all ADs will be covered right away. Orthotics, prostheses and respiratory equipment will be covered first.

Coverage for wheelchairs, seating and ostomy supplies may come last.

Bills should be saved in case of retroactivity.

- 2) Ontario March of Dimes Assistive Devices Program.

The Ontario March of Dimes is at present the funding agency for assistive devices, including home alterations. Advocacy in relation to assistive devices is a routine component of the service.

- 3) Vocational Rehabilitation of the Ministry of Community and Social Services will pay for assistive devices in order to allow people to: go to school, become or remain employed, be a homemaker for self and at least one other.

- 4) New assistive devices.

Sunnybrook Hospital and the Hospital for Sick Children are likely to have information on the latest services. Orthopaedic physicians should be asked to advise on their relative merits.

- 5) Braces.

Participants went through their specialist for the first brace, then went directly to Sunnybrook, Ottawa, Kingston or other rehabilitation department, with physician's referral.

Older polio people do not want to change from the many older braces that they have become used to, to the new lighter ones. It was found out that many braces would not help the problem of fatigue, and so people should make the effort to adjust to the lighter braces. There was a feeling that one had to negotiate with the bracemaker in order to get what one wanted. Why can't braces be worn with fashionable shoes instead of traditional oxfords?

6) Other services.

Sunnybrook Hospital provides braces, shoes, prostheses, seating and neuromuscular assessments. There are plans for communications aids. A referral is required. Ontario March of Dimes Assistive Devices Program will help if it is difficult to get a referral.

7) Orthopaedic shoes.

There are just two orthopaedic shoemakers in Toronto, but neither will take new customers. These shoemakers were thought to be a "dying breed". Pedorthists who do lifts and other customizing are coming in from the United States. Little was known about their services.

8) Education of professionals.

Post-polio people should try to ensure that physicians, OTs, physios and nurses become better educated about polio. Post-polio associations should approach the various professional associations.

In one of her many magnificently lucid moments, Audrey King once remarked to me in her own inimitable and articulate way, that a gathering of post-polios was not dissimilar to a gathering of war veterans, in that one could count on experiencing three things: sharing, camaraderie, and finally, a spirituality which was not quite akin to religious experience. Throughout the day, and especially as I visited each workshop this afternoon, that is exactly what I experienced: excellent sharing, splendid camaraderie, and what was personally surprising for me, an extraordinary sense of spirituality.

I have been given the difficult task of wrapping up in a few minutes, this long and rewarding seminar. I would like to do this by making a few recommendations and sharing one or two of my thoughts with you.

First of all, I would like to suggest that the initial recommendations in the complete March of Dimes report to be prepared about this seminar, should reflect carefully any concerns or recommendations about future programming which the various workshop representatives have just expressed and put forward.

Secondly, concerning the workshop about support groups or networking, I would like to say that I think that much of the information which was shared could very well form the basis of a handbook about networking which would be extremely useful to local associations in the future. Concerning local post-polio associations, it would appear that there is a need for several more to be formed throughout the province in the near future. I would like to suggest that the process of initiating these new groups should ensure continuing support for provincial March of Dimes thrusts and priorities and at the same time, encourage the kind of local autonomy which will result in effective and creative programming at the grass roots level.

I would like to suggest that this morning's excellent presentation about the March of Dimes survey of post-polio problems should be repeated and perhaps somehow shaped into a travelling workshop for physicians and other medical personnel.

I would like to recommend that in its dealings with the government, the March of Dimes use this survey as a rationale for the establishment of an assessment centre for post-polios.

Concerning Dr. Feldman, I would like to recommend that we invite him back some time. I would also like to suggest that the March of Dimes explore with Dr. Feldman the possibility of assisting him in the further documentation of the effectiveness of his innovative and interesting approach to exercises for post-polios.

I would like to suggest that March of Dimes make full educational use of the video tape that is being made today, that it be available somehow, by rental or sale to local groups and other groups that could really benefit from it.

Finally, I would like to thank the staff of March of Dimes and the volunteers from the Toronto/Peel and Ottawa Post-Polio Associations for an excellent seminar and for providing the local associations with an exemplary model from which to develop their programming.

