

POLIO NETWORK NEWS

International Polio Network

4502 Maryland Avenue
St. Louis, MO 63108 U.S.A.
314/361-0475

Polio Network News is an international newsletter for polio survivors, support groups, physicians, health professionals, and resource centers, to exchange information, encourage research, and promote networking among the post-polio community.

Editor:
Joan Headley

Publisher:
Gazette International
Networking Institute
(G.I.N.I.)
4502 Maryland Avenue
St. Louis, MO 63108 U.S.A.
314/361-0475

Joan Headley, *Executive Director*

Annual Membership:
U.S.A.: Individual \$8; Health
Professional \$15; Institution \$25
CANADA/MEXICO & OVERSEAS (Surface):
Individual \$10; Health Professional \$17;
Institution \$27
OVERSEAS (Air): Individual \$15; Health
Professional \$22; Institution \$32
(U.S. dollars only)

Copyright © 1989 by
Gazette International Networking Institute
4502 Maryland Avenue
St. Louis, Missouri 63108 U.S.A.
Permission to reprint portions must
be obtained from the Editor.

Fall 1989 ■ Vol. 5, No. 4

Research Reports from Fifth International Polio & Independent Living Conference

Neurological Research

By Raymond Roos, M.D., University of Chicago,
Chicago, IL

I want to discuss three research directions we at the University of Chicago and elsewhere are involved in. I'll very briefly describe analyses of the neuromuscular junction (the nerve and muscle junction) in post-polio individuals, studies looking for immunological or virological abnormalities in post-polio individuals, and molecular studies of the polio virus and related viruses to learn more about why motor nerve cells die.

But first, let's review a previous study that tried to answer questions still very much on our minds. What laboratory studies differentiate post-polio syndrome individuals from post-polio individuals who have no new weakness or functional disturbance? How can we make the diagnosis of post-polio syndrome from a laboratory point of view? What's the cause of post-polio syndrome?

When he was at the University of Chicago, Dr. Neil Cashman led a group of investigators, including the moderator Roberta Simon and me in studying post-polio syndrome. We did muscle biopsies and electrical studies on post-polio individuals with and without post-polio syndrome. As a result of the studies, we can report these findings.

First, no laboratory study differentiates post-polio individuals from non-weakening post-polio individuals. In other words, using conventional electrical studies and muscle biopsies studies, we really can't see a statistical difference in these two groups. The reason is that there is ongoing nerve damage in members of both groups (non-weakening and weakening post-polio individuals). Another finding is that there is evidence of ongoing denervation

(continued on page 2)

Research Reports *(continued from pg. 1)*

that is associated with very large motor units. In acute poliomyelitis the motor nerve cells that innervate these muscle fibers die. The remaining living motor nerve cells have to take over a larger number of motor fibers and consequently these motor nerve cells have to do more work. This seems to be associated with progressive nerve problems and the question is whether these terminal sprouts of the motor nerve cells are the problem.

We decided to answer with an anconeus muscle (small muscle in the forearm) biopsy which is used for neurophysiological research. Dr. Ricardo Masselli of the University of Chicago and me are very much involved in this study now.

Morphologically, we're able to get the muscle itself and do special staining. Dr. Robert Wollman is looking at the actual terminal sprout of the motor nerve itself to discover if there is a problem in the sprout. Does it show a lot of anatomical abnormalities?

We're also able to do electron microscopy to look at the actual terminal nerve and the muscle itself (neuromuscular junction). We studied the neuromuscular junction of another neuromuscular disease that shows fatigue as a prime clinical symptomology-myasthenia gravis. So we are especially interested in the nerve-muscle junction in post-polio individuals. The neuromuscular junction in a post-polio individual and the anconeus is very different from the normal appearance. We're midway in these studies currently analyzing this data. We are looking very carefully to determine if this is the site of the problem in post-polio syndrome.

Let's talk about the relationship of the syndrome to a viral or immune abnormality. It's interesting

to note that viruses similar to polio can persist for a long time in the central nervous system. It's not supposed to be true with polio and I don't want to leave anyone with the wrong impression. I don't think that a virus is present in post-polio syndrome individuals. On the other hand, from a scientific point of view we want to look very carefully, and at least one investigator found some abnormalities of the immune system in post-polio syndrome individuals. (There were bands of immunoglobulin in the spinal fluid when frozen by an electrode.) This is very common in multiple sclerosis. We've just completed a study looking at the spinal fluid in post-polio individuals, and out of the twenty spinal fluids that we looked at, none of the individuals had bands except for the one who also had multiple sclerosis. So we found no evidence of any immune abnormality in post-polio syndrome.

Lastly, I might ask the question, "What can the study of polio virus infections in the study of post-polio syndrome teach us in a very broad sense?" One of my interests is that we're going to learn about factors key to the survival and death of the motor neuron itself. Remember the polio virus is very selective. It only kills and infects motor nerve cells. What's interesting is that the living vaccine that is presently given for polio is in fact alive. It will replicate in the human body, but it doesn't paralyze.

Based on the work of others, we are now able to clone in sequence the parental strain of the polio virus and the very rare revertant mutants that may cause paralysis after vaccination. We now know that the vaccine strain that Sabin developed is actually a mutation that occurred during passage of the parental strain. And we know now exactly what the key mutation is that takes this nonparalytic parent

strain and makes it a vaccine strain.

We can also take the Sabin vaccine strain and mix it with the parental strain and make recombinants of the genes. Each of these genes can be made into a virus which is tested to determine how paralytic it is. So, in other words, we know now exactly what part of the gene of this virus and viruses related to polio viruses causes paralysis or causes death of motor neurons. This is important not only in understanding what kills motor nerve cells but in making the perfect vaccine. As I mentioned, we have very good vaccines, but as a result of this kind of work we will be able to make changes in the genes so that we'll never get a revertant case of poliomyelitis from the vaccine strain itself.

Conclusions From Omstead County

by Anthony J. Windebank, Mayo Clinic, Rochester, MN

My talk this morning may sound like cold statistics, but each of these statistics is a person that I've worked with, and I know from each one I've learned something about coping on a long-term basis with the problem. Our moderator spoke about individuality and I think that is a very important thing to bear in mind when looking at these statistics.

A group of us has been studying a population of individuals who had polio between 1935 and 1955. This group is different from other groups because these individuals all lived in Omstead County, which is the county around the Mayo Clinic in Rochester, Minnesota. And these individuals were not seeking medical attention. The people that we've been looking at represent everybody who had polio in this county. We've been trying to define what is happening in this population as a whole, not just in

individuals who are reporting difficulties or coming to clinics. We are able to draw conclusions because Omstead County has a fairly typical North American population.

We were very rigorous about defining "persons who have had polio." All fulfilled the diagnostic criteria for poliomyelitis that was drawn up in 1949 and also fulfilled the diagnostic criteria for having paralytic myelitis. How many people did we find? Of 608 identified cases of polio, 300 were paralytic cases and 53 individuals either died during acute polio or have died subsequently.

From the group of 247, we randomly selected 50 individuals to study in detail. We looked to see whether they represented our group as a whole. Our group of 50 individuals has the same kind of distribution of weakness as the group as a whole. We looked at sex ratio and the age at the time of polio. We've have the actual medical records, so we're not dealing with memories of what happened.

We heard earlier that in Taiwan everybody who had polio was very young. The median age was two. It's interesting to note in our population that the average age was 13 and this was much more typical of the United States population.

Our detailed study included a questionnaire, a clinical examination, a disability score sheet, and the Minnesota Multiphasic Personality Inventory (MMPI). We also did some special tests: creatine kinase level, pulmonary function tests, muscle strength tests in our mechanics laboratory, and some electrophysiological studies.

I would like to highlight some of the things that we have learned. The 330-item questionnaire asked about almost every aspect of life involving muscle function. From that questionnaire, there were 55 items that would indicate if

(continued on next page)

Research Reports (continued from pg. 3)

individuals were experiencing some sort of progressive difficulty. The kind of difficulties we saw were typical of what had been reported in other series. We found that fatigue alone, as a symptom, was quite unusual. Two individuals reported just fatigue. Similarly pain alone as a new symptom was quite unusual. Seven of the 50 individuals reported only pain and in every case it involved the axial skeleton, so there was neck or back pain. And these were all people who had involvement of the axial skeletal muscles during the polio. Many of them had scoliosis (curvature of the spine). Combinations of weakness, new weakness with fatigue or new weakness with pain, or a combination of weakness, pain, and fatigue were more common.

If you asked very detailed questions, 32 of the individuals (64%), were experiencing some new type of difficulty. When considering how this affected their function on a daily basis, only ten of the individuals reported using new aids or changing their occupation or activities. Most of the individuals who were using new aids, like bath rails or leg braces are in their 30s or 40s. This is not just something associated with aging. And, in fact, one of the things we looked at is whether age is a factor. We were quite surprised because we thought age or length of time since you had polio was going to be a major factor.

If you compare people who are having new difficulties and people without new difficulties with their present age and the age at which they had polio, the statistics are completely identical. Age and interval since onset, in this group, don't seem to play a part in the development of new symptoms.

I would stress the results of MMPI (Minnesota Multiphasic Personality Inventory) testing that we did. Is

depression more common? Are individuals who are experiencing more difficulties more likely to be complaining? The answer was "no." We did not find any differences at all. Polio survivors who were having new difficulties were not complainers. They were identical to the group who were experiencing no new difficulties, and they were also identical to an age match population. In this group, we didn't see any psychological influences or influences of personality.

We also found that the electrophysiology or an EMG does not distinguish between those who are having new difficulties and those who are not.

We found many different indicators of respiratory function. In this group we did not find any significant changes in the vital capacity and any differences in respiratory function between those who were having difficulties and those who were not. As a group, respiratory function was preserved very well.

What we did find that was very clear was the major correlation between reporting of new symptoms and the amount of weakness that a person had originally in a limb. For example, if you had a weak left leg or weak right arm, you were much more likely to be reporting difficulties in that limb. And in fact, we did not find any reports of new difficulties in limbs that were clinically unaffected by the polio during the acute illness. We think that's quite an important finding.

We did find a relationship between the likelihood of reporting difficulties in arms and legs. People with leg weakness were twice as likely to be reporting difficulties with arms and legs as people with equally weak arms. So this does seem to show some relationship to weight-bearing.

In conclusion, this study found a number of things. There was no

difference in the psychological profiles, the pulmonary function studies, the age and intervals since polio, between people who are experiencing new difficulties and those who are not experiencing new difficulties.

There's no doubt that in this group the major determinate of new symptoms was how much of the body was affected by the original polio. The 50 individuals who were studied in detail for this report will be restudied next year after a 4-year interval. We then will be able to measure the changes in these individuals and correlate the changes in muscle function with all of the variables we have discussed.

In conclusion, I would like to mention that this research has been supported by the Easter Seals Research Foundation and we look forward to their continued support.

Study & Trial Treatment of Diaphragmatic Fatigue

By Patricia Gilchrist, P.T.,
University of Alberta Hospital,
Edmonton, Alberta

I'm speaking on behalf of Dr. Rubin Feldman. Under his direction, the post-polio syndrome clinic at the University of Alberta Hospital in Edmonton has been functioning for 11 months. The clinic is funded by the Royal Canadian Legion and was preceded by a three-year period of research using non-fatiguing strengthening exercises to treat post-polio affected muscles and post-polio malfunctions.

People who are candidates for post-polio syndrome are referred by family physicians to us based on their clinical presentations. Dr. Feldman assesses the polio survivor and uses electromyography to test selected muscle groups. Individuals who have post-polio syndrome are referred to the physical therapist for treatment.

Fifty-five to 60 individuals will have received treatment in the first year of clinic operation. Some of these individuals have complaints of headaches, shortness of breath on exertion in the absence of cardiac problems, restless sleep, and feelings of weariness, even in the morning. In cooperation with the respirologist at the hospital, they have been examined for crural muscle fatigability using electromyographic (EMG) examination of the crural muscle of the diaphragm.

In preparation for the EMG of the diaphragm, the individual is sent for pulmonary function testing. (This will be repeated later to monitor any change.) An x-ray of the chest is taken using a lead pellet marker on the spinous process of T-11. From this, the radiologist can indicate the level of the posterior plural recess, and the EMG needle will be introduced below this level. The person is trained to use an inspiratory resistor device (P-Flex resistor) in order to provide an exercise factor during testing.

The EMG is performed with the person in a sitting position. A finger oximeter is used to monitor oxygen saturation. A 50-mm EMG needle is introduced through the intercostal space and lateral to the right paraspinal muscles. Progress is followed through the external and internal intercostals and then into the crural muscle. Individuals don't complain of pain after needle entry through the skin. With the needle in place, the individual breathes on the P-Flex resistor until fatigue is reached and then for a few more breaths.

The EMG readout is recorded on the computer. A power spectrum analysis is done to indicate the fatigue pattern. As a result of the test, the number of breaths that can be performed prior to fatigue on a known level of resistance is known.

(continued on next page)

Research Reports *(continued from pg. 5)*

This information is used to develop an exercise program to be monitored by the physiotherapist. The goal is to improve the strength and endurance of the diaphragm. This is done by starting exercise with half the number of breaths performed during the EMG prior to fatigue and on the same resistance.

This parallels the program used for peripheral muscles in the clinic. Individuals increase the number of breaths on the P-Flex resistor. They are doing exercises daily at home and twice a week with the physical therapist. When the resistance is no longer challenging, it is increased, and the number of breaths is reduced to initiate a new level of training. To date, six individuals have been examined, and three are on the exercise program. Subjective results are positive, but the necessary objective data to confirm changes has not yet been collected.

However, diaphragmatic action with and without resistance has been examined during fluoroscopy and shows a marked increase in diaphragmatic descent with the use of resistance. It also shows gradual reduction of descent as fatigue is perceived by the trained patient. Paradoxical movement of the diaphragm in an individual with chronic respiratory fatigue has been seen on a crural muscle EMG. There is now interest in using the P-Flex resistor treatment to try to reverse the paradox in some controlled cases of respiratory fatigue by training people in P-Flex use. This trial is in process.

Although the EMG is accurate and relatively straightforward, it is invasive. Consideration is being given to the use of the Borg Scale, which is a 15-graded scale of ratings of perceived exertion. This study is intriguing and raises many questions regarding work with the diaphragm in people with chronic

respiratory disease as well as those with post-polio syndrome.

This introduces our work to date which is funded by the Special Services and Research Committee at the University of Alberta Hospitals.

Cardiovascular Conditioning for Polio Survivors

By Richard Owen, M.D., Sister Kenny Institute, Minneapolis, MN

I'm going to report on our research studying conditioning exercises for post-polio people. This study, by good fortune, is going to be published next week (June 9, 1989) in the Journal of the American Medical Association (JAMA). One reason I'm pleased about the appearance in JAMA is that it is a national journal that goes to primary care doctors. This is a group of people who need to know about post-polio syndrome.

The complicated and interacting factors that are responsible for post-polio problems are still not fully understood. In fact, beginning with the initial group of people we started seeing in 1982, we were impressed with the significant level of cardiopulmonary deconditioning in individuals with post-polio syndrome. Some experienced fatigue, and that fatigue sometimes expressed itself in weakness in local muscles and sometimes in a generalized fatigue. But those are factors experienced by individuals who are deconditioned whether they've had polio or not.

The purpose of this study was to determine whether we could do an adaptive cardiopulmonary conditioning exercise program successfully in individuals with post-polio residuals without damage to polio-involved musculature. We also wondered if we could achieve an adequate level of cardiopulmonary conditioning.

We had a volunteer group of post-polio people which biases the study. They had post-polio residuals that had been identified as polio-related. They had an absence of intercurrent health problems, and they were all good-natured people who were pleased to get together in the summertime in Minnesota. They had adequate strength to push one pedal of an exercise bike and adequate time to commit to exercise three times a week for a 16-week period.

We set an age limit of 60 years and evaluated our volunteers for appropriateness in the group. They were pretested with a pulmonary function test, pulmonary function test with exercise, a stress test, and tests of muscle strength.

The experimental group carried out cardiopulmonary conditioning three times a week for 16 weeks. The interval training technique built up the heart rate to a point of the resting heart rate plus 70 to 75% of the reserve heart rate. The heart rate usually gets up to about 130 or 140 beats per minute. The individual is permitted to rest for one to two minutes after a three- to four-minute period of biking. The total exercise time was 20 minutes not counting the rest periods.

The control group met monthly, and they were advised not to do anything differently. In Minnesota in the summertime people do things differently than they do in the wintertime. For instance, they get out of the house and do something besides shovel snow! As a consequence, the control group actually got a little bit better in some areas. They were in a little better shape by the time summer was over, but the interesting thing was that they didn't improve as much as our exercise group.

The age range of the exercise group was 29 to 56 years. The maximum oxygen consumption improved by 15%

in the test group, which represented an improvement similar to what you would see in a non-disabled population doing the same exercise program. One question we had was whether a significant cardiopulmonary conditioning program can be done by people who have lower extremity weakness. In fact, it can.

The total work of the quadriceps muscle increased by 26% on the right and 34.2% on the left. This was measured by the Cybex. We confirmed what people at the Sister Kenny Institute proved years ago, that manual muscle testing is not accurate. Individuals we thought had grade 5 strong muscles were still, in general, lower than the average population.

The average power in the total work increased in extension of the thigh; the cardiopulmonary conditioning level increased; the exercise group enjoyed the protocol and recognized carryover in endurance in daily activities. Three-fourths of the control group decided they wanted to participate in cardiopulmonary conditioning on the completion of this study.

Thirty people from our first two study groups wanted to volunteer for our third project because they enjoyed coming out and exercising with other human beings who were having similar experiences. I think this is the mystery factor in doing any research on human beings. There is a community spirit that carries people some distance.

Also, at Sister Kenny we finished an ergometer arm exercise bike study, which was fascinating because most of the literature would suggest that ergometry wouldn't do the cardiopulmonary conditioning that an exercise bike does. In preliminary studies on cardiopulmonary conditioning the increase was 15%, which comes awfully close to the 16% that we achieved with the exercise bike.

(continued on next page)

Research Reports *(continued from pg. 7)*

Our current study is on the parameters of cardiopulmonary conditioning. Can we do it over a shorter period of time? Is there any benefit to alternating it with some other program? Our studies have been funded by the National Institute for Disability Research and Rehabilitation (NIDRR). This was my idea, but Dr. Jennine Speier our Director of Clinical Research hired a statistician and they did all the work.

Neuromuscular Function: A Comparison

By James C. Agre, M.D., Ph.D.,
University of Wisconsin Medical
School, Madison, WI

I'd like to thank the Easter Seal Research Foundation for their support, without which I'd have no information to present to you. In the last two years, we studied individuals who had polio and who were either complaining of progressive problems, weakness problems, problems from recovering from fatiguing activity, or individuals who had polio who were not complaining of such symptoms. We also had a group of age-matched controls in our study.

Of 104 individuals, we had a total of 34 symptomatic polio subjects, 16 asymptomatic polio subjects, and 41 control subjects in our study.

All of the symptomatic subjects complained of progressive weakness and general loss of endurance in muscles. The muscle group that we studied was the quadriceps--the muscles on the front of the thigh that help to straighten the knee. All the individuals in the symptomatic group acknowledged that this particular muscle group was undergoing progressive loss in function.

We had all our polio subjects fill out a specific questionnaire and all subjects completed a general health questionnaire. All subjects underwent testing to look at the strength of the quadriceps muscles. We did that with a fancy dynamometer which could measure the strength of the muscle to the nearest pound of force.

All the subjects in our study had at least grade four strength in the quadriceps muscles. That is, all of the polio subjects in the study could straighten the knee against gravity with some resistance.

We also looked at the work capacity of the quadriceps. We had all the individuals in the study push against the arm of the dynamometer with their ankle. A feedback mechanism allowed them to see how much force they were using and all subjects pushed at 40% of their maximum strength. They held that isometrically as long as they possibly could. The range for all our subjects was somewhere between one and three minutes. All the individuals indicated their perception of exertion throughout that test.

At the start of the endurance test, the subjects were asked to rate their level of exertion. We used a scale called the Work Perceived Exertion Scale, which has numbers from six to 20 corresponding to a work level of less than very light to a work level of greater than very hard. Every twenty seconds throughout the test I would ask the individuals to rate their perception of work that they were doing. Needless to say, all subjects throughout the test went from levels of light to very hard.

After exhaustion was reached, we tested for recovery of strength. Every thirty seconds for the first 2 minutes after the test the individuals gave me 5-second maximum effort, and then minute by minute they gave a 5-second maximal effort. We examined how much force

they were able to exert during that time and compared that to the force they were able to generate before that endurance test.

Following this, we did an EMG of the quadriceps muscle to see from a quantitative point of view how severely affected the quadriceps muscle was by initial polio. Evidence of denervation and of ongoing problems was noted.

We looked at twenty individual motor units so we could examine the sizes of the motor units. With re-innervation following original polio, motor units would tend to become larger.

We found significant differences comparing our symptomatic group and our asymptomatic group. When we looked at the history, we found that the symptomatic group of polio survivors seemed to have more severe polio. On the questionnaire the average duration of hospitalization in the symptomatic group was somewhere over five months. For the asymptomatic group it was just over one month.

On the EMG test we found that the symptomatic group also was more severely affected by original polio.

The size of the motor units on the symptomatic group was two and a half times as large as those in the asymptomatic group. They happened to be five to six times as large as those in the control population. This was evidence of more severe polio involvement in the symptomatic group.

When we looked at muscle strength, we also found a very significant difference. The symptomatic group had about 60% of the strength of the quadriceps muscle as the asymptomatic group. In fact, the asymptomatic group was almost as strong as the control group.

When we looked at endurance time, (how long individuals were able to hold the previously described endurance test at 40% percent of their maximum strength), we saw no difference in all three groups. Everyone at the same relative level of effort had similar endurance.

However, when we looked at the work that was performed, we found that the symptomatic group was so much weaker that they did much less work. They did half the work that the controls did and about 60% of the work of the asymptomatics.

Our symptomatic subjects not only were more severely affected by polio early on but had less strength and less working capacity up to the point of exhaustion.

The story doesn't end there, though. We looked at how readily muscle strength recovered after this fatiguing exercise.

Our symptomatic group had more difficulty recovering strength than the asymptomatic and the control groups. The asymptomatic and control groups were able to recover their strength completely over a ten-minute period, whereas our symptomatic group was only able to recover 90% of their strength.

We found several differences between these two groups. It certainly makes sense to me that individuals who are complaining of neuromuscular symptoms may have neuromuscular problems when we look at strength, work capacity, and recovery. And that seems to correlate with the severity of polio early on.

Another important part of the study was the perception of exertion. We found that perception of exertion was the same in all three groups, and that is important clinically speaking. Although someone cannot do as much work, they can perceive the muscles getting tired. Our symptomatic polio subjects tend to

(continued on next page)

Research Reports *(continued from pg. 9)*

have more problem recovering strength. If they listen to the muscle, rest, and pace themselves before they reach fatigue, we think they can do a lot more work with less overall fatigue. The bottom line that we are recommending from what we have found is the importance of listening to your body and pacing yourself.

Exercise and Fatigue in Post-Polio Survivors

By Michael J. Fillyaw, M.S., P.T.,
University of Vermont, Burlington

We are now in the 17th month of an on-going research project sponsored by the Easter Seal Research Foundation to study the changes in muscle strength and fatigue which occur during a two-year home-based progressive resistance exercise program in individuals with post-polio syndrome.

Although recent reports have shown that resistance exercise programs lasting for less than six months can improve muscle strength in some individuals with post-polio syndrome, the effects of resistance exercise done over a long period of time and the effects of muscle fatigue are still unknown. Indeed, there continues to be concern that exercise may cause overwork and accelerate muscle weakness.

The purpose of our study is to determine the short- and long-term effects of a resistance exercise program as assessed by mechanical and electrophysiological measures of muscle strength and fatigue.

In addition, at the conclusion of the study we plan to do a retrospective analysis to determine if any measurement taken on or before the onset of the exercise program prognosticates the later change with exercise. This would help therapists to know which individ-

als may benefit from exercise and which may not.

Twenty-five individuals with a history of paralytic polio have been enrolled in the exercise program. Twenty-three meet the diagnostic criteria for post-polio syndrome that was proposed by Doctors Halstead and Rossi. The other two subjects did not meet this criteria but because of their interest in the exercise program were permitted to join. To qualify, the subject first must have a minimum of fair strength in both quadriceps muscles in the thigh. That is, in a sitting position you must be able to straighten the lower leg fully at the knee. And second you have to have a needle EMG examination which shows changes consistent with both muscles having been affected by polio. The biceps muscles in the arm may be substituted for the quadriceps if either criteria is not met for the quadriceps muscles. Finally, they can have no medical condition that would prohibit them from undergoing exercise testing training.

Of the 23 subjects with post-polio syndrome in our study 18 are women, five are men. Their average age is 51 years, but they range from 33 to 77. The onset of these symptoms occurred about 37 1/2 years after their acute polio. Everyone reports fatigue as one new symptom; about two-thirds of the people report new muscle or joint pain or have new muscle weakness or atrophy. Only about half of our subjects have noticed an increase in muscle twitching or fasciculations.

The exercise program is a modification of the traditional progressive resistance exercise approach that is used in many physical therapy clinics. It is based on the amount of weight a person can lift ten times through a full range of knee motion. This is called their working weight, and that forms the basis for the exercise program. At the first test visit one quadriceps

muscle is assigned by random selection to be the exercise muscle, while the other is left to be the control. In this way, each person serves as his own control. The control muscle does not do the resistance exercise, but the person is not otherwise restricted from engaging in the normal activities of daily living.

The exercises for the exercised muscle are performed at home every other day using ankle cuff weights, which we provide. The exercises are done in three sets of ten repetitions per set with a five minute rest period between sets. Progressively more weight is lifted in each set. First 50%, then 75%, and finally 100% of the person's working weight. After approximately two weeks of exercising on that schedule, subjects try to complete 15 repetitions with the full working weight during the third set. Successfully completing fifteen reps indicates that the weight is too light and should be increased on the next exercise day.

We have everyone complete an exercise diary where they record the amount of weight lifted each day and any other questions or problems that may have arisen. The diary provides a historical record of exercise compliance during training. In addition, at least once a month I phone each person to find out how they are doing, to discuss any problems that they may have encountered, and to help them set a new working weight should this be necessary.

Cybex II isokinetic dynamometer is used to measure strength and muscle fatigue. With the aid of a personal computer which is connected to both the Cybex and an EMG amplifier we can simultaneously record both the force and the surface EMG activity produced by the muscle when the subject pushes out against the pad attached above the left ankle. At the end of the study we will conclude if the exercise has

been beneficial by analyzing four measures of muscle strength and fatigue. Our subjects come back to the laboratory for testing every three months.

Two of the measures are mechanical in nature. The first, maximum torque, is a way of measuring force or maximum strength. The second, the fatigue index, is the percent decline that occurs during a 60-second maximum isometric contraction, and is a measure of muscle fatigue. The other two measures, neuro-muscular efficiency and median frequency, are based on an analysis of the changes of the EMG signal which occur during that 60-second muscle contraction and are also ways to characterize muscle fatigue.

Because we are now in the middle of the study and have not done any formal analysis. I am unable to report to you any final results. However, I can say that the exercise program seems to be well received and well tolerated. Thus far only three people have dropped out of the study, two for reasons unrelated to the exercise program itself. One person did have to drop out because of an increase in chronic lower back pain which prohibited her from continuing the exercises. Thus far, no one has had to discontinue the exercise because of increased fatigue or weakness. Compliance with the exercise has averaged about 75%, that is to say that everyone is exercising about three out of every four days they were scheduled to exercise, which indicates the overall support and interest in the program. Finally, all have increased the amount of weight that they are able to lift, on the average almost double what it was at the start of the exercise program.

Conference reports will be continued in future Polio Network News.



Status of Polio in India

Dr. S. Jones was Director of the Central Marine Fisheries Research Institute in India when he contracted polio at the age of 53. After his personal recovery from polio, Dr. Jones recognized the overwhelming need for comprehensive rehabilitation. He started the Home for Handicapped (Polio) Children in 1974, and today it contains the most modern facilities for rehabilitation and is considered one of the best of its kind in Asia.

As he approaches 80 years of age, Dr. Jones is compelled to inform the world of the status of polio in India and to educate his government and his people about the options available for polio rehabilitation. Each year in India, 275,000 individuals contract polio. Statistics show that 90,000 survive with a disability and 30,000 die.

Addressing the Fifth International Polio and Independent Living Conference in St. Louis last June, Dr. Jones commented on the state of medical help, "They are not bothered about the condition once a child is paralyzed. Treatment thereafter is only in terms of a blacksmith and calipers (braces). I want to emphasize the need for bridging the gulf between the polio attack and the rehabilitation."

Dr. Jones announced the Conference on Polio Eradication and Post-Polio Physical Rehabilitation in the Indian Region, January 30-February 1, 1990. The conference will be held at the Home for Handicapped Children in South India.

The opening session will present the status of polio eradication in the region followed by sessions dealing with the various aspects of physical rehabilitation.

Anyone who can assist in this effort should contact Dr. S. Jones, Home for Handicapped (Polio) Children, LMS Compound, Trivandrum 695 033, Kerala, India. (Trivandrum-63724.)

Networking Success

IPN forwarded Dr. Jones' conference invitation to Dr. H. V. Wyatt, 1 Hollyshaw Terrace, Leeds LS15 7BG, United Kingdom, who had spent some time in India studying injections and active polio. IPN was delighted recently to learn that Dr. Wyatt has received a grant from Save the Children Fund to travel to India to assist Dr. Jones in organizing the conference for the Indian region.

Dr. Wyatt is also interested in reaching Maltese who had polio in Australia, Canada, etc. Please contact him at the above address.

福 A Special Thank You

Mrs. Herbert Cammerer and Mr. Jack Wilson wish to thank the many friends throughout the Network for their condolences following the death of their sister, Gini Laurie.

Thank you to all individuals and organizations who contributed to the Gini Laurie Endowment. The income from the fund will be used to continue Gini's work.

FOR YOU TO CONSIDER

Rebound from Crisis: Hidden Power to Confront Late Effects of Polio
By Paul Rau, Greenville, SC

The success of the Salk and Sabin vaccines remain virological milestones in the elimination of polio epidemics since 1955-62. However, polio as an illness still challenges medical science with the unexpected residual complications from the initial viral onset. Equally important and possibly misunderstood is the latent power of the total immune system. More than 25 years after the success of the Sabin vaccine, we still do not understand how the polio virus recultured many times with the tissue culture procedure can remain viable, but as a vaccine, it loses the capacity to cause paralysis.

This report will concentrate on some of the psycho-social aspects of the immune system. These aspects permitted young children with polio to confront the paralysis of the initial onset by an "overcome" philosophy. The grieving-coping process allowed them to re-enter society with new skills and attitudes for pre-existing tasks changed by the residual effects (disability) of the acute stage of polio.

A metaphor is suggested for a better understanding between the physical (antibody titer) and the psycho-social (emotional) aspects of the immune system, as related to polio. "Apparel manufacturers can treat the fiber with a surface coating (such as Scotchguard) to prevent permanent staining or penetration of the contaminant to enter the core of filaments." Fibers used for such a fabric are selected by their ultrastructural detail which permits transport of air for comfort control without permitting contamination to core. The polio vaccine is similar to the surface

coating in preventing contaminant penetration. The psycho-social immune response is the spontaneous feeling process (overcome philosophy) which facilitates the "comfort control" to accept unexpected core level changes.

Rebound from crisis is a learned process resulting from effective confrontation of a core level loss (such as paralysis) in the normal grieving process using an overcome philosophy. This then becomes a part of our immune system in a similar fashion to the antibody titer. Just as the polio antibodies become part of our biological defense system, transformation from a core level loss prepares the psycho-social aspects of humans for a second disability. A conscious effort must be made to tap this latent power for a second disability.

Many polio survivors during the acute stages of the illness were too young to realize that the remarkable recovery was through a self-help program which required active cooperation of the young patient, parents, physicians, and significant others. This self-help alliance resembles the self-help program described by Norman Cousins in his book, The Anatomy of an Illness, and also had some of the ingredients in the self-help movement modeled after Alcoholics Anonymous. Denial as a coping mechanism was an effective method for recovering from the initial stage of polio, but continual use of an outdated road map can be a hindrance to the existing residual of polio as a progressive chronic illness. Polio survivors can rightfully be called pioneers in rehabilitation by the transformation process of therapy and the overcome philosophy, and by use of the following positive types of discipline:

1. Effective confrontation of pain, commonly referred to as "delayed gratification," accepting responsibility for the illness. "I must do

(continued on next page)

it alone and not let feelings interfere with recovery."

2. Becoming involved with the reality of the illness through a bond of trust with parents, physicians, therapists, and friends.

3. After the initial convalescence, the polio survivor began or returned to education with a special self-motivation and compensation in lifestyle to minimize or ignore any disability from polio.

4. Perhaps most importantly, during the Great Depression the U.S. population elected a paraplegic from polio, Franklin D. Roosevelt, President, even though he could not stand or walk alone. He became a powerful role model for many children with polio. The most important significance of FDR's success in confronting and transforming himself from the paralysis of polio is that he was able to "rebound from crisis" and be elected president of a country for four terms, a feat that has never been equaled.

Many polio survivors (approximately 300,000 to 500,000) living in the United States today also have been successful people because of the transformation from the first crisis.

Shortly after the first medical symposium on late effects of polio, Hugh Gallagher's book, FDR's Splendid Deception was published. Based on this book, it appears that historians, society, and possibly the author himself, failed to recognize that Franklin Roosevelt was a great man and became a great president because he had rebounded from crisis through therapy and an overcome philosophy, and had effectively confronted paralysis from polio. Equally important and perhaps totally ignored by the public was the dedicated support of his family and close associates who remained in the background, but who

were an essential part of this great world leader.

Many polio survivors having been forced to confront a core level loss from polio and then transformed by therapy and an overcome philosophy, can again tap the hidden power to rebound from a second disability. Am I, as a polio survivor, ready to follow FDR's example by using the power of the mind and body learned from a disabling illness? Am I willing, with the cooperation of others, to show society that self-discipline and delayed gratification learned as children can be as much a part of our lives and immune system as the early belief that I must do it alone? The process of restructuring the overcome philosophy to, "You alone can do it, but you can't do it alone" will require a mature decision to modify our road map of life because many polio survivors, especially children, buried the pain and negative feelings of crutches and hot packs without learning how to ask for help.

We should focus on rebound from crisis and the high level of discipline used in the overcome philosophy cited in Scott Peck's book, The Road Less Traveled. This was learned as children and recently updated by self-help programs (support groups) to help us understand the late effects of polio. We can transform the disability from polio into a strong ally and teach society that polio survivors are true pioneers in rehabilitation.

We can demonstrate that polio as an illness is a prototype of how to live with any chronic illness. The psycho-social aspect of their immune system through the use of their "rebound from crisis" will be the hidden power to confront and live with the late effects of polio.

FOR YOU TO CONSIDER

"I enjoyed reading your article. Most of us were completely taken by surprise when the syndrome began to appear. We did recognize that some people might have weakness resulting in scoliosis but in those people who seemed to be perfectly normal we did not anticipate any further difficulty. In retrospect, you are probably correct that people who had recovered, apparently completely, should be followed, and their areas of weakness identified and, as you say, protected."

Frederick C. Robbins, M.D.

Dr. Robbins, Dr. J. F. Enders and Dr. T. H. Weller of Harvard won the Nobel Prize for the discovery that polio virus would grow in tissue cultures of non-nervous human tissue.

A Post-Polio "Normal's" Reconciliation with the Ghost of Polio Past



By Sandy Hughes Grinnell,
Independent Medical Researcher,
Pasadena, CA

My purpose in writing a detailed medical history of my own case in narrative form for the International Polio Network is two-fold: first, to provide a study that can be further evaluated by polio specialists in the medical community; and second, to serve as a resource for post-polio normals to use in their efforts to establish credibility with regard to their belief

that they are indeed experiencing new symptoms stemming directly from old polio.

By writing about my own case publicly, I hope that some of what I learned will help others to help themselves. To those of you reading this article who wish to begin your own research efforts, the important thing is to jump in with both feet and do your best!

I am defining a post-polio normal as a person with a well-documented history of polio who has in recent years or is presently experiencing one or more late-effect symptoms but continues to function without any ambulatory aids, adaptive equipment, or respiratory assistance.

"How can it be that I am experiencing post-polio symptoms?" I asked Dr. Jacquelin Perry at the Polio Clinic at Ranch Los Amigos Medical Center in Downey, California. "It has always been assumed that I had made a complete recovery." She gently put her hand on my shoulder and said, "My dear, you must understand that polio comes like a thief in the night, and when it leaves it takes part of you with it."

Dr. Perry used that simile in August of 1984. It had a powerful impact on me and would forever symbolize a major turning point that gradually enabled me to make order out of chaos regarding my understanding of and control over my stamina-related health problems of many years. In the five years since I've been to the polio clinic to be evaluated, I've come up with the following analogy for those of us who make up the post-polio population:

In all of our interactions with people, first impressions greatly influence our perceptions, and most of this initial reaction is based on how we appear on the outside. There is an old saying that "A picture's worth a thousand words."

(continued on next page)

For the most part, I would agree, but in the case of a post-polio normal that picture is often an illusion because many of us who look so solid and healthy on the outside are like slices of Swiss cheese on the inside. Just as Swiss cheese comes with big and little holes, many of us are experiencing a range of symptoms which have variations in size. Ironically, for years we substituted muscles so efficiently in ways that we were completely unaware of that we, in effect, totally camouflaged those invisible holes, which are referred to in the medical literature as "uneven levels of muscle strength."

In my opinion, the post-polio normal walks (literally and figuratively) a middle ground. We have a documented history of polio which we minimized for years because it conjured up "ghostly" images of wheelchairs and crutches and in the worst cases life support systems such as the "iron lung." For reasons often thought of as no less than "miracles" by our families and friends, we re-entered the part of the population that had never been infected by this disease. We are only now beginning to learn that in our eagerness to fit in again, we have been putting some of our muscles under exceptionally high levels of stress. I personally reached a point in my life where I had to seriously question the validity of the claim that I had made a "complete recovery" and hope that my doctors would share in my skepticism.

Ironically, even after I had been to the polio clinic in 1984, was thoroughly evaluated, finally diagnosed in writing as a "post-polio normal," and had acknowledged the fact that I must slow down in order to stay independent, there was a part of me that wanted to run the other way. At that point the segment of the polio population with visible residuals became a living

ghost to me--a vivid reminder of what could have happened years ago and if God were playing a bad joke on me, could still happen now. I think it is important to note that this had been the first follow-up visit with polio specialists since my recovery from the initial illness in 1953 at age ten. The chain of events that lead up to that appointment began in the early summer of 1984.

In June after recovering from an episode of lower back spasms which had required two weeks of bed rest and some physical therapy to relieve, my orthopaedic surgeon was feeling a combination of concern and increasing frustration with my unrelenting and more frequent back problems as the years progressed. After all, since he had become my doctor in 1975, my records showed that I had experienced 19 episodes of lower back pain leading up to this most recent one! X-rays showed a very mild narrowing at the lumbar 4-5 interspace in my lower back, but it was not felt to be solely responsible for such numerous attacks.

In the medical summaries I had forwarded to me, it was always noted that I had "bulbar" polio in 1953 (involving the part of the brain at the top of the spinal column), but no connection was made to ongoing episodes of incapacitating spasms. On several occasions between 1975 and 1984, I asked my orthopaedist if he thought my recurring upper and lower back problems could be related to my history of polio. He definitely did not think so, but he, like my other doctors at the time, had not been trained in the ongoing treatment of polio patients while in medical school. Whatever doubts I was sometimes beginning to have were suppressed by my doctors' consistent opinions that there was absolutely no connection to old polio.

In June of 1984, my orthopaedist suggested I get into a swimming

class as soon as possible. We both knew swimming was not at the top of my list of favorite sports for exercise, but I had literally exhausted every other option. Each of the 20 episodes since 1975 had been the end result of some new sport I had taken up (tennis, golf), a new hobby I had pursued (dancing, painting workshops, acting), or a job that I held in a creative field (fashion display work). My orthopaedist and I agreed that an aerobic swim class might be the answer because it would combine swimming and dancing to music in water and would minimize any shock to my spine. I proceeded to have a bicycle EKG and some generalized fitness tests for endurance to see if I could also get into some low level Nautilus program in an attempt to develop more muscle strength. The tests were going smoothly until I tried to bench press a bar bell with no added weight, and I not only could not lift it off my chest, I couldn't even hold it above my chest without assistance from the instructor.

As had always been the case since my college days, things started out great! I was going three times a week, and the first week I felt energized. During the weekend before the fourth class, however, I began to experience a very localized tiredness and cramping in my chest and upper back, and my breathing was somewhat labored. I forced myself to go to the Monday class and halfway through the class I felt as though my muscle strength was now regressing, but I pushed myself (as usual) to finish.

What I experienced for the next 72 hours I thought to myself had to be felt to be believed. The only time I ever had that kind of a pain syndrome that I was aware of was when I was admitted to the hospital in 1953, in the acute stages of polio. It is important to note that at the time I was experiencing this pain and exhaustion in my upper body, I

had not heard of or read one word about post-polio problems. Muscle relaxants and aspirin were giving me no relief whatsoever. The only thing that helped was rest. I remember that the feeling was beyond what I could logically comprehend. Tears were running down my face in physiological reaction to the pain.

The fact that I was in excellent health as far as routine physicals go prompted me to find some recent articles on reactions to aerobic exercise that might explain my situation. After a couple days of total bed rest, I decided to venture over to the library. While I was there I noticed my arms and hands were so weak and cramped I could barely lift the reference books, and the repetition of turning pages was beginning to become extremely difficult. As more time elapsed, I felt a lessening of hand coordination.

Finally, when my breathing became labored, I immediately called my internist. After summarizing my symptoms of the past few days, he sounded as perplexed as I was. He speculated that perhaps it was an acute anxiety attack causing hyperventilation. I told him that unlike anxiety attacks that (no matter how overwhelming and incapacitating they are) come intermittently during a 24-hour period, and cause generalized body weakness, my "attack" had been completely localized, involving my chest, upper back, and arms. The symptoms were unrelenting in nature and only began to subside after many hours of complete bed rest. I mentioned that I had not felt this much pain in my spine since I'd had polio as a child.

Luckily, a young intern sitting near the phone at the library that day, overheard my remark about having had polio. By coincidence, he told me that he had recently read a newspaper article quoting Dr. Richard Bruno at Columbia University in which he cited cases

(continued on next page)

Reconciliation *(continued from pg. 17)*

of a seemingly sudden loss of muscle strength approximately 30 years after the onset of polio and problems with pain and loss of function in the hands. (I would later learn that the muscle strength loss was a gradual process over many years, with the cumulative effect being experienced as a sudden drop in function about 30 years after onset.)

Upon reading the article about Dr. Bruno's research for myself, I decided that the first thing I had to do was to document my case with my own medical records of polio. I had several long distance phone conversations with the medical clerks at the hospital where I had been cared for in 1953 and was devastated to be told that after a thorough search, it was confirmed that my records had been destroyed in a fire back in the 1960s.

I then called my parents to find out what they could remember about my stay in the hospital. They told me that the head of the polio ward at the hospital I was admitted to was Dr. Frederick C. Robbins of "Enders, Weller, and Robbins" fame who won the Noble Peace Prize for polio research which would make possible the development of the Salk and later the Sabin vaccine. Through my local hospital library I found out that he was currently President of the Institute of Medicine at the National Academy of Sciences in Washington, D.C. I wanted to write to him about my present situation, but in view of the fact that 30 years had passed and I had no medical records of polio available to forward to him, I decided against it.

There would be someone from my past, however, who would be instrumental in getting me the help I needed. In the mid 1970s, while volunteering in the children's ward at Orthopaedic Hospital in Los Angeles, I had the good fortune to

become acquainted with Dr. Thomas Gucker III. He was at the time Assistant Medical Director of the hospital and a well-known orthopaedic surgeon and medical research scholar. He himself had had polio as a youngster, requiring a leg brace for walking. Now in July of 1984, I re-established contact with him by phone, and he invited me to drop by his office for a visit. He first encouraged me to be evaluated by Drs. Armin Fischer and Jacquelin Perry (both top polio specialists) at Rancho Los Amigos Medical Center in Downey, California. Since Dr. Perry had been his personal physician for a number of years, he proceeded to set up the appointments personally. (He did not think he himself had post-polio related problems and was at first skeptical of my symptoms being related to old polio--in view of my level of recovery. I would remind him in months to come, regarding his initial skepticism, that in his case, due to years of coaching by Dr. Perry to "slow down and protect his energy reserves" long before her advice was available to the post-polio population at large, he probably was spared getting into trouble in the first place. He conceded that may have very well been true!)

Arrangements were made for me to be seen at the polio clinic in August of 1984. My first appointment was to be with Dr. Armin Fischer, who would later co-author the now established Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors. Since "looking so normal" had always worked against me in the past when trying to relate my problems to old polio, when I did finally meet Dr. Fischer in person, the first thing I said to him was: "I want to ask you a favor. I have been blessed in this life with looking physically fit. Therefore, I'd like you to look at me through your ears, so to speak, today and give me a totally objective hearing regarding my recurring symptoms before you

make any evaluation." He proceeded to give me over two hours of his valuable time and even though I had been unable to get the formal records of my polio case from 1953, based on what I described to him that day, he would later write in his summary evaluation of our visit: "Her symptoms of fatigability and weakness may very well relate to overuse syndrome that has been seen in patients with residuals of poliomyelitis." With reference to my need to rest for longer periods of time between periods of more intense physical activity and my reaction to my most recent aerobic swimming attempts, he notes: "She has noticed muscle tenderness, most prominently in the pectoral regions, and she does feel discomfort in the parasternal region... associated with cramping and fatigability and has complained of weakness in her hands...she finds she has to rest sometimes for a day following intense physical activity." (Note: The pectoral muscles are in the chest and the parasternal region refers to the area of the breast bone. Chronic weakness and fatigue in this area can affect breathing and, as I understand, can cause a form of hyperventilation that could be thought to be symptomatic of severe anxiety when not properly diagnosed.)

As I read and re-read his report, the medical terminology used to describe my symptoms seemed so similar to something I had read about myself before, but I could not remember where. Later on, as I began obtaining just about every medical record that had ever been kept on me (except my original polio records) an old report arrived from a hospital in Santa Barbara, California, where our family had lived in the 1960s. It was from the Department of Orthopaedics, stating that I had been seen in the Fall of 1966 suffering from upper back spasms. In describing the source of my problems the report said in part, "There is marked tenderness to palpation of the

entire interscapular musculature and in the definite nodules of the musculature." (Note: the interscapular musculature refers to muscles between the shoulder blades. These muscles in part include the trapezius muscles, some of which I would later learn were creating a lot of my upper body weakness.) It is also noted that I have been seen in the past years with similar complaints especially during intense periods of continuous writing when taking college exams.

This information was important to consider in view of an article in the 1980 issue of the Rehabilitation Gazette by well-known polio specialist, Dr. Frederick Maynard, in which he stated with regard to late effects of polio: "Symptoms in case studies have begun as early as eight years or as late as 57 years after onset of the disease." Upon reviewing my various medical records one more time, I calculated that my lower back problems requiring medical attention began in 1962, only 9 years after the onset of polio. The recurring pain between my shoulder blades and chest began in 1963, only 10 years after the onset, and with increasing intensity requiring medical attention beginning 13 years after the onset.

The possibility that there was a pattern all those years that could be directly traced back to my history of polio became highly probable in view of the muscle resistance tests that were performed on my entire body at the polio clinic in 1984. (To be continued in the Winter Polio Network News.)

The original version of 15 pages may be obtained from IPN for \$2.50 (photocopying and postage.)

Reactions to "For You to Consider" should be mailed to Paul Rau, 204 Great Glen Road, Greenville, SC 29615 or to Sandra Hughes Grinnell c/o of IPN.

POTPOURRI

1990 Easter Seal Research Grants

Research grants for projects that impact the treatment and management of disabilities are now available from the National Easter Seal Society's Easter Seal Research Foundation.

Trustees for the Easter Seal Research Foundation (ESRF) will meet in March 1990 to review proposals and award grants. Funds for up to \$40,000 are available for projects. ESRF encourages projects that relate research outcomes to improved rehabilitation and other services provided for people with disabilities.

For additional information, write to Norman D. Grunewald, Vice President, Easter Seal Research Foundation, 70 East Lake Street, Chicago, IL 60601.

Volunteers Needed for Research

A graduate student in the School of Nursing at the University of Missouri, Columbia is looking for polio survivors over 50 to complete questionnaires on symptoms, health perceptions, and coping responses. All information will be confidential.

Interested persons should contact:
Reng K. V. Winters, RNC
544 Pear Tree Circle
Columbia, MO 65203
314/449-3585

Renewal Notices

Revised renewal notices were mailed in October to individuals whose subscriptions are due this quarter. Please remember to notify IPN of your new address when you move.

Americans with Disabilities Act (ADA)

The ADA was reintroduced in Congress, in a modified form, on May 9, 1989. On August 2, a bipartisan version was adopted by the Senate Committee on Labor and Human Resources (16-0) and was endorsed by President Bush. On September 7, an amended form was passed (76-8) by the Senate.

The House is considering the ADA (in late October) and will vote in the next few weeks. Contact your representatives and urge them to pass the ADA unamended.

Leaders' Workshop

The biennial Support Group Leaders' Workshop is scheduled for June 8-10, 1990. The program will be developed during the next few months. Please contact IPN with your ideas and requests.

Support Group Leaders Write...

CABLE TV COMMUNITY ACCESS

Many cable companies provide a public access channel to fulfill agreements with their local governments and to promote public relations with their communities. The public in turn can provide programs for the community access channel as long as the following requirements are met (in Atlanta, Georgia).

You must attend a workshop to learn the fundamentals of doing a television show and a workshop on the techniques of doing a show.

If you are still interested in doing a program, you can present a proposal which consists of six program ideas. If your proposal is

accepted, you then assemble a working crew (director, camera man, sound man, etc.) and produce your programs. All six must be completed before any is aired.

A member of Atlanta Post Polio Association (APPA) who had previously taken the fundamental workshops presented a proposal for taping our monthly meetings. The cable company supplied a list of "directors" and suggested she get one to assist with the programs. After finding a director, she presented a written proposal to the cable company.

The cable company wants your first six programs to be done "in house" so that they can monitor your work, but by using a director who had field experience, we were able to tape our monthly programs. (We were able to produce our six programs with no problem, because APPA has an outside speaker for the monthly meetings with a rap session scheduled every third meeting.) Our monthly programs vary from coping techniques to descriptions of home health aides.

By taping our programs, we accomplished several objectives. First, we have a library for new members. Second, we have programs that will inform everyone in the community of the late effects of Polio and the assistance available for any individual with a disability. Third, we have a means of letting health professionals know about us without their having to attend meetings.

Prime Cable TV in Dekalb County is now participating in what is called "bicycling." They will exchange our monthly polio programs with another cable company. If anyone is interested in exchanging programs, please discuss the idea with your community access cable TV coordinator and ask them to write or call Ms. Carol Barton, c/o Prime Cable TV, 2818 Ponce de Leon Avenue, Decatur, Georgia 30030 (404/378-0294).

The tapes could be a way for support groups to have experts for a program without travel expense. If you have any questions regarding APPA's cable TV programs or their audio/video library, please contact Theresia Arnold, 1506 Bates Court, NE, Atlanta, Georgia 30319 (404/636-1392).

Cookbook for Sale

Texas Polio Survivors' Association (TPSA) has published a cookbook, "Cooking Across Texas." The book which contains over 400 recipes can be purchased by mailing \$10 plus \$1 for postage to TPSA, P.O. Box 35688, Houston, TX 77235-5688.

Polio Network News' **Readers Write . . .**

Cold Intolerance

For years I struggled with intolerance to cold temperatures. I have found Damart Thermolactyl Clothing to be helpful. I especially like a fabric called Double Force. I tried cotton, I tried wool; Double Force is better. It's warmer and lighter, thus more comfortable to wear. When requesting a free catalog, be sure to ask for information on Damart Thermolactyl and Double Force, as they sell a wide range of clothing. The address is: Damart, 3 Front Street, Rollinsford, NH 03805.

Virginia E.Hord
Dayton, OH

Involuntary Eye Movements

Two polio survivor friends and I have been bothered by involuntary eye movements which can be described as tremors, spasms, or muscle contractions. It is not at all

(continued on next page)

Readers Write (continued from pg. 21)

painful but it is very annoying. We would like to know if other survivors are having a similar problem or if it is just coincidental.

Gertrude Steiman
47 Bayberry Drive
Sharon, MA 02067

The Cutter Incident

Do you know about the "Cutter Incident" of the spring of 1955? I am trying to obtain information regarding this incident because I suspect I contracted polio by receiving a vaccination from one of the lots produced by Cutter Laboratories. It is quite difficult to obtain information 34 years later. I am slowly tracking down excerpts from articles. I would appreciate any information you might have.

Mrs. Regina A. Crowell Batalgia
1715 Leon Drive
Forest Grove, OR 97116
503/357-5430 or 503/681-1586

Adhesions After Surgery

I have used a wheelchair for 35 years. I drive a car with hand controls and ride a horse three times a week. I am currently recovering from abdominal surgery which is the same situation I was in 18 months ago. Since polio, each surgery results in extremely uncomfortable adhesions. Perhaps someone might be able to share knowledge about this type of situation.

Mrs. Frank H. Low
33 Joan Drive
Chappaqua, NY 10514

Live in Northwest Arkansas?

We do not have a support group in our part of the state, and I would like to communicate with other polio survivors. Please ask your readers from the Fayetteville area

to write to me if they are interested in a group.

Jewel Cole
1721-B Reap Drive
Fayetteville, AR 72703

Live Near Springfield, MO?

With the assistance of our community college, I am forming a support group in the Springfield, MO area. Please ask your readers to contact me if they are interested.

Catherine Kelly
617 West Greenwood
Springfield, MO 65801

Share Information

Because of my father's heart attack, I could not attend the Fifth International Polio & Independent Conference last June. I had hoped to make acquaintances who would share information with me after I had returned to India. Perhaps some of your readers would like to write to me. I am a 35-year old polio survivor who works in a publishing house.

Rajesh Rawal
8/182, Sunder Nagar
Naranpura Char Rasta
Ahmedabad 380 013
Gujarat, INDIA

Post-Polio Directory

The 1990 Post-Polio Directory will be published in February. All additions, deletions, and changes should be forwarded to IPN by January 10, 1990. Everyone now listed will receive a form before the holidays to confirm the facts. This form must be returned to IPN by January 10, 1990.

Please ADD the following:

CLINICS

Dr. James Little, M.D.
Skin Rehabilitation
One Siskin Place
Chattanooga, TN 37034
615-265-2200 (January 1, 1990)

HEALTH PROFESSIONALS

Dr. Brevard Haynes, M.M.
St. Thomas Hospital Sleep Disorder
Clinic
Suite 311, 4230 Harding Place
Nashville, TN 37205
615-385-1946

Dr. E. Michael Gutman, M.D.,
F.A.P.A.
Psychiatrist
2501 N. Orange Avenue, S-411
Orlando, FL 32804
407/896-1324

SUPPORT GROUPS

Atlanta Post-Polio Association
Theresa Arnold
1506 Bates Court, N.E.
Atlanta, GA 30319

Central Jersey Post-Polio SG
Joseph Rubin
209 North Rossmoor Drive
Jamesburg, NJ 08831
609/655-9036

Lowcounty Post-Polio SG
Shirley M. Youmans
2630 Otranto, Apt. E10
North Charles, SC 29418
803/797-3491

Pittsburgh Area
Carrie Kaufmann
5700 Bunkerhill Street
Pittsburgh, PA 15206-1166
412/661-5997

Lewis & Thurston Co. Polio SG
Jennie Beth Mac Cannell
1117 Mellen Street
Centralia, WA 98531
206/736-7339

W.A.P.P.S.G.

P.O. Box 1123
Bunbury, Western Australia 6230

P.P.N.W.W.A.
Para Quad Centre
Shenton Park
6 Selby Street
Perth, Western Australia

Please make the following CHANGES:

SUPPORT GROUPS

Polio Echo
Ellen Pilcher
P.O. Box 61024
Phoenix, AZ 85082
Western: 602/877-1972
Eastern: 602/949-9649

Post-Polio SG Foundation, Inc.

Sue Conner
437 Lockhaven Drive
Hot Springs, AR 71913
501/767-5314

Simi Valley Post-Polio SG

Melody D. Hobson
2005 Denny Street
Simi Valley, CA 93065
805/581-4697

Pat Bubeck

Capital Area Post-Polio SG
1119A Grove Road
Harrisburg, PA 17111
717/541-4330

Central Virginia Post-Polio SG

116 North Boulevard
Richmond, VA 23220
804/355-7166

Polio Survivors SG

Sally McMillin
201 Richmond Heights Road
Bristol, TN 37620
615/764-9734

Gunnel Skoglund

Riksförbundet för Trafik
och Polioskadade
Box 3027
171 03 Solna
Sweden

CLINICS

Dr. Trevor Paris, M.D.
Tennessee Christian Medical Center
500 Hospital Drive
Madison, TN 37115
615-865-0300 ext 4577

International Polio Network
GINI
4207 Lindell Blvd., #110
Saint Louis, MO 63108-2915 USA
314-534-0475

Non-Profit Org.
U.S. Postage
PAID
St. Louis, MO
Permit No. 17

ADDRESS CORRECTION REQUESTED
FORWARDING AND RETURN POSTAGE GUARANTEED

© 1989-1990

Calendar

November 2-5, 1989. First Pacific Northwest Regional Conference: Managing Post Polio Problems. Airport Inn Resort, Richmond, British Columbia. Contact: Rheta Davidson, 1701 Cedar Hill Cross Road, Suite 402, Victoria, British Columbia V8P 2P9. 604/477-6546.

May 23-25, ¹⁹⁹⁰ ~~2000~~ Post-Polio International Conference: Poliomyelitis-A Forgotten Disease and its Late Effects. Galt House, Louisville, KY. Contact: Frances Brown, 6203 Fegenbush Lane, Louisville, KY 40228. 502/239-9792.

June 8-10, 1990. Support Group Leaders' Workshop. Sheraton St. Louis Hotel, St. Louis, MO. Contact: Joan Headley, International Polio Network, 4502 Maryland Avenue, St. Louis, MO 63018. 314/361-0475.

October 13, 1990. N.J. Conference on the Late Effects of Polio. Somerset Marriott Hotel, Somerset, NJ.