

POLIO NETWORK NEWS

International Polio Network

Fall 1991 ■ Vol. 7, No. 4

TES Therapy

Catherine Bell, Kingston, Ontario, Canada

I had my last major treatment for childhood poliomyelitis — a muscle transplant involving my left foot — when I was eleven. Thereafter, I was able to consider myself normal and during the next 25 years the fact that I had ever had polio faded from my mind. In 1987 it came back to disrupt, if not actually destroy, my life. However, my purpose here is not to bemoan a fate with which too many of my readers will be familiar but to give an account of a therapy that last winter enabled me to go for a walk through knee-deep snow without support, cane, or even fear of collapse.

I contracted polio in 1953 at the age of two. It affected my legs from the knees down badly enough that I had a long hospital stay and several transplants before I learned to walk again. With the final operation at age 11, I was able to walk normally and, through high school and college, to participate in most sports that did not involve a lot of jumping.

By 1973 I had become a knitwear designer in Toronto, and my early encounter with polio was largely forgotten. In a job where I was on my feet all day, it was easy to believe it had, in fact, never happened.

This was also true while doing the most enjoyable but physically exhausting part of the designer's job — travelling. To stay on the leading edge, designers must go see for themselves what the rest of the world is wearing. For over a decade I travelled with my employer, a man six feet tall who walked like a fireball and mentally photographed every memorable outfit or store window to be seen. I am only five feet two-and-one-half inches, but yet I was always able to keep up with him as we walked the streets more than eight hours a day for up to two weeks at a time. That is, I was able to keep up until 1987.

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People Keep Coming: The Brief Story of a Support Group

Sunny Roller, Ann Arbor, Michigan

Karl Menniger once said that "attitude is more important than facts," and as a support group leader, I think his idea is accurate and applicable. Facts are critical, but "attitude is more important than facts."

The fact was in 1984 there was an unconnected group of people in the Ann Arbor, Michigan, area who were showing up at **Dr. Frederick Maynard's** Post-Polio Clinic complaining of new pain, weakness, and overall fatigue. They were feeling out of control, alarmed, confused, afraid, and even panicked about the unexpected decline in their abilities to function. Down the hall from the doctor's clinic was a bright, capable, vocation rehabilitation counselor named **Liina Paasuke** who was experiencing the same late effects of polio. She could not get around as well on her braces and crutches. She, too, had gone to see Dr. Maynard about this strange new problem.

About the same time, I hobbled into the hospital building desperately seeking help for new pain, weakness, and fatigue, having totally exhausted all of my personal resources and coping tactics in search of a solution. I saw Dr. Maynard as a patient and Liina as a counselor. Dr. Maynard suggested to Liina that she start a support group for all of the people he had been listening to in his clinic. Liina turned to me and said, "Sunny, let's start a support group." I turned inward and said, "Who, me?" I answered, "I guess I have the time and it does seem like a good thing to do." So we did it. We did not know what to expect, and the fact was, I was a little scared to be in a group that was strictly composed of people with disabilities.

This month marks the sixth anniversary of the group that became the *Post-Polio Connection*. We have been meeting regularly since February of 1985. We have a mailing list of 340 with an average attendance of 15. We have never concerned ourselves with trying to draw large numbers of people to meetings, which have ranged from 70 attendees to four. We like to focus on quality rather than quantity.

From the start, Liina and I decided that we wanted to

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People Keep Coming

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promote positive attitudes to counteract the negative new facts we were hearing. We assumed that polio survivors were seeking new health and balance. To offset the new pain, people needed a little pleasure. To counteract the weakness, they needed strength. And to alleviate fatigue, they needed new sources of energy.

We had 12 people at our first snowy winter's meeting. In spite of their mild, moderate, and severe disabilities, they came and expressed their fears with sophistication and sensitivity. They talked about what they had to share with one another as group participants. Here is what they said ... "a sense of strength" ... "which is knowledge that we are blessed and grateful for what we have" ... "a knowledge that we are not alone — there is hope" ... "a place to just be ourselves" ... "a place to find total acceptance as a person that day" ... "through the group, an ability to say, 'what are we going to do about it?'" ... "a place to receive and regenerate, to refresh, and renew" ... "an environment where we are very concerned with helping each other."

The format for our group meetings became like a seminar, rather than a therapy group. Liina and I had no group model, so we did what seemed logical and possible. People were most in need of education about polio's late effects and a warm support came as a strong outgrowth of our educational programming. We have hosted speakers who present information and lead a follow-up discussion on topics that members predetermined were important and relevant — doctors, psychologists, directors of local helping agencies, social workers, occupational therapists, physical therapists, massage therapists, political

activists, dietitians, and spiritual leaders. They have told us the facts. We have worked on the attitudes.

Our group has two goals: 1) take a positive approach to our lives in general, and 2) problem solve and increase our perceived options in regard to our polio experience in particular. Liina and I agreed from the start that we did not want to lead or be part of a group that sat around complaining and whining and then went home sad and discouraged. So we acknowledge problems, but consciously end our meetings on a positive note. As we more fully embrace our "post-polioness," we want to feel more enabled when we leave our meetings, not more disabled.

Our focus now is different from our initial focus. Most of us old timers stabilized by our fourth year in the support group. We are here now to keep learning, enjoying each others' company, and now we validate and help the new people who come to the group. We have gone from meeting once a month to once every other month.

From the leaders' point of view, Liina and I have decided that we have had a couple of organizational struggles. One has been frustration with our inability to pinpoint any potential leaders among the ranks who will volunteer to take our positions. People in the group do not want to be too taxed, which is a part of the post-polio syndrome itself. So, at this point in time, we have light-heartedly resigned ourselves to a lifetime commitment as group coordinators. It is comfortable, now, because we only meet six times a year, and the group supports us as leaders. They do the mailings, bring the refreshments, and participate enthusiastically at meetings. Everyone seems to genuinely accept one another which is very energizing for all of us. Liina and I often have felt guilty because we do not publish a newsletter, organize group talent

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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.

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shows, or personally initiate and facilitate intense therapeutic dialogues at every meeting, but we are both not only working full-time, but also experiencing post-polio physical declines and have had to set serious limits to our leadership. We organize meetings, line up the speakers, write the meeting announcements, provide literature, and have that under control. Members donate \$5 per year to pay for the room rental at the church, for meeting refreshments, and for cards and flowers that we send to members who need extra support between meetings.

Our membership is fluid. We have had people drop out because the group was not disabled enough for them or because they were not disabled enough for the group. We had one member die of a heart attack in her mid-forties which was very sad, and two members who are at mid-life just announced their engagement to marry each other. Other people have dropped out because they discovered what they needed to know and went on with their lives. Old members leave and come back. New members find our core group of about ten people faithfully attending every meeting.

Six years after the first snowy afternoon meeting, people keep coming. We have, through those years, made better friends with our polio and with each other. Meetings have given us a chance to collectively validate our original polio experience. We have each told our story and witnessed that there is great healing power in social support.

Attitude is more important than facts. The fact is: we in the support group have the late effects of polio which we never planned on, and we do not relish the continuous coping. It is Liina's and my hope that our *Post-Polio Connection* will continue to nourish positive empowering attitudes that reconfigure the facts, so they are not simply bearable, but become actual avenues to new maturities and life-building opportunities.

Sunny Roller, Coordinator of the Post-Polio Research and Training Program at the University of Michigan Medical Center in Ann Arbor, Michigan.

Sunny presented the above at the *Post-Polio Conference III — Perspectives for the Nineties* held in Oakland, CA, last February.

TES Therapy *(continued from page 1)*

The first sign was greater than usual general fatigue and wobbly legs around the design studio and sewing rooms. I gave up high-heeled shoes and was often exhausted by mid-afternoon. Then at home, my leg gave way and I tumbled down a whole flight of stairs. My husband took me to hospital emergency department to treat my torn ligaments. The result was a plaster cast. I was only 36.

It was, of course, a painful reminder of the long ignored fact that I had once had polio. I was soon sent to West Park Post-Polio Clinic which said that I had post-polio syndrome. More precisely, they determined it was a significant loss of strength in my left quadriceps which caused the knee to give out and the leg to collapse.

To cope with the situation, I began using a cane. At first it was an old wooden cane which was lent to me by a friend, and I felt very old and wooden. I soon visited Cane and Able, a business specializing in canes and walking sticks, and surrounded myself with a beautiful cane wardrobe.

The problem rapidly became worse, and my husband insisted on installing chair-lifts in our three-storey house. Now that a trip to the corner store had become an ordeal, my employer lost his travelling companion. I began using an electric scooter just to get around the factory. To deal with the mid-afternoon exhaustion I

took a twenty-minute cat-nap after lunch, and, as part of my new "conserve to preserve" life-style committed to not over-tiring the remaining good muscles, I also gave up the part-time teaching that had enriched my life in recent years. To maintain flexibility, I entered into hydrotherapy so I could exercise without fatigue.

It was during a hydrotherapy session in 1989 that I met another polio survivor who was taking part in a new research programme under the direction of **Dr. Karen Pape** at the **Toronto Hospital for Sick Children**. A year earlier, faced with a three-year-old whose birth spinal injury left her unable to sit or breathe unaided, hospital doctors had tried running low frequency electrical charges along neural pathways in a bid to stimulate muscle growth and use. In the case of this child the "nothing to lose" treatment had been so successful that the use of the therapy had been extended in an experimental programme funded by the Ontario March of Dimes.

By now, my post-polio problems had changed my life. I had given up my job. One compensation was that I was able to pursue my earlier interest in teaching but that was not much consolation for having to retreat from the front lines of an occupation I loved and a position of which I was proud. My husband and I realized we would have to move to a bungalow, and where I once joined him on evening strolls without a second thought, I now regarded a half-block walk to

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buy a quart of milk as something akin to running the marathon.

Given all this, I came to believe that I, too, was in a "nothing to lose" situation and asked Dr. Pape and the children's hospital to accept me into the experimental **Therapeutic Electrical Stimulation Programme (TES)**. They gave me several base-line tests and on April 8, 1989, I underwent a Magnetic Resonance Imaging Scan (MRI). Thereafter I was shown how to apply the therapy. I took home a small, battery-powered neuromuscular stimulator. Six nights a week I attached electrodes to points on my left leg carefully chosen by TES doctors and slept with the machine pulsing on and off. The charge is so low it is barely noticeable. In fact, the children who now make up the bulk of TES patients call it The Tickle Machine.

Within six weeks I began to notice a slight improvement in my leg: better balance, improved circulation and slight growth in the wasted muscles. As the months passed I had no doubt that TES was helping. However, I had to wait a year before Dr. Pape could perform another MRI, and at that time the demonstrable change was sufficient enough that I was given a second stimulator in order to work on both legs at once. By then, the TES programme had graduated from its early experimental status and both patients and staff, led by Dr. Pape, had moved to **The Magee Clinic**, a new clinic set up in north Toronto.

I have been on TES for two years and can demonstrate a remarkable improvement in the strength in my legs. Six months after starting TES — that is 18 months ago now — my husband and I moved to the university city of Kingston, Ontario, where I now teach fashion design full-time and where we finally bought that bungalow. At first, even the five steps to the ground from the front door were a threat, and my fear of a leg collapsing under me tended to make me something of a prisoner in my own home. Now I walk down them without bothering to cling to the railing, a garbage bag under each arm. I still carry a cane and may even use it if I have to line up for something, but usually I leave it in the car. I keep the electric scooter on campus, although I must confess I am more likely now to use it as a way of carrying a double load of schoolwork than as a necessity to travel from class to class. I still take hydrotherapy, but I also swim lengths in a regular pool. I rarely think twice when my husband asks if I will keep him company on one of his evening walks, and last winter I even found myself tramping through knee-deep snow in our local park.

A recent MRI shows significant improvement in my leg muscle density. It is impossible to scientifically determine whether what I feel is totally accurate, but I feel that I have regained at least 75 per cent of the strength and stability I originally had before I began to experience post-polio syndrome four years ago.

Dr. Pape and her associates at The Magee Clinic warn me there is no guarantee how much more I will regain, or, indeed, whether I will actually regain any more strength at all. They also point out there is no way to predict the long-term effects of this therapy, since it is still in the research stage. What I do know, however, is that when I want to go for a walk it is no longer a major decision. For the moment, the freedom to be able to leave my house, to walk up a flight of stairs, to go buy a quart of milk ... the freedom to do just these things alone, without having to carefully weigh the possible consequences, is precious.

Dr. Karen Pape, Magee Clinic, 5160 Yonge Street, Suite #505, Toronto, Ontario, M2N 6L9 Canada (416/733-1783 or 416/733-1721).

CANE RESOURCES

Cane & Able, 263 Main Street East, Cambridge, Ontario, N1R 1X6, Canada. Call 519/623-4518 or write Jill Summerhayes for an appointment.

Thanks to Linda Crabtree and Charcot-Marie-Tooth (CMT) International, One Springbank Dr., St. Catharines, Ontario, Canada, L2S 2K1, for sharing the following information on canes:

The Hummers, Inc., Reagan Wells Canyon, Box 122, Uvalde, TX 78801 USA. Jim Lee of Uvalde, Texas not only does beautiful decorative woodworking but has another shop in Austin that does nothing but make walking sticks and staffs.

Lumex, 100 Spence St., Bay Shore, NY 11706 USA (1/800/424-2458). Lumex makes a cane with a light in the handle that illuminates a house or car keyhole and canes with four legs on the bottom called quad canes.

The Cane Connection, 5500 Harford Rd., Baltimore, MD 21214 USA. Call 301/426-6000 or write for a free catalogue called **Walking With Distinction**.

Boserup House of Canes and Walking Sticks, 1636 Westwood Blvd., P.O. Box 24156, Los Angeles, CA 90024 USA, also has a catalogue.

Duro-Med Industries Inc., 301 Lodi St., Hackensack, NJ 07602 USA. Write for information on lucite and wood canes, folding canes, tripod canes, a cane seat, an adjustable Pic-up Cane Reacher, the Duro-matic Retractable Ice Cane, and a walker that is part cane, part walker.

Linda suggests that you ask for a price list with the catalogue, as most companies have separate price lists that change during the year. Also ask for the name and address of the retailer nearest you that carries their product.

Anaesthesia: Considerations for Polio Survivors

Polio Network News: Dr. Spencer, we have received several requests for information concerning "the danger of administering certain anaesthetics to polio survivors." Please clarify the issues.

Geoffrey T. Spencer, OBE, MB, BS, FFARCS, Consultant, Department of Anaesthetics, Lane Fox Respiratory Unit, St. Thomas' Hospital, London, England:

The problem is not straightforward, but our experience is described in *Perioperative care in restrictive respiratory disease*, J.A. Patrick, M. Meyer-Witting, F. Reynolds and G.T. Spencer, *Anaesthesia*, 1990, Volume 45, pages 390-395. The article suggests that with suitable modification to take account of the disability, general anaesthesia is no more dangerous for people who had polio than it is for anybody else, and our views are summarized in the conclusions.

There is a fundamental difference between British anaesthetic practice and that of the States. We do not have nurse anaesthetists; all anaesthetics are administered by doctors. We believe that administration of anaesthetics by nurses substantially alters clinical practice in that techniques have to be standardized and routines established. This tends to make it more difficult to go back to basic considerations and modify techniques to meet particular needs.

Special considerations for polio survivors can be grouped roughly into three categories: those resulting from the general effects of polio, those resulting from respiratory insufficiency as a result of polio, and those resulting from the surgery to be undertaken.

Special consideration for polio survivors resulting from the general effects of polio

Patients with significant paralysis from polio have a greatly reduced muscle mass. Muscle normally contains a great deal of blood and requires a substantial blood supply to function. If much of that mass is lost, the total blood volume is greatly reduced, and such patients react to haemorrhage as does a small child. This necessitates precise and complete replacement of blood lost during surgery. Most patients with polio replace lost muscle with fat. Very few remain as thin as they were immediately after the acute illness. Fat contains a smaller proportion of water than does muscle, so the effects of water loss are more quickly apparent and electrolyte disturbances, particularly potassium loss, require careful and precise balance and replacement.

Special consideration for polio survivors resulting from the respiratory effects of polio

Most general anaesthetics depress breathing. Mechanical respiratory assistance, during and after anaesthesia, in polio patients whose breathing is even mildly

affected by polio is essential. It often needs to be maintained for longer, postoperatively, than would be necessary in a non-polio patient undergoing a similar operation. Most postoperative painkillers also depress breathing and need to be used with caution. Surprisingly, perhaps, this is not as much of a disadvantage as it sounds. A great deal of postoperative pain is due to muscle damage caused by surgery. If muscles are absent or weak, pain is proportionately less severe, and the need for painkillers is thereby reduced.

Special consideration for polio survivors resulting from the effects of surgery

Many surgical operations require the passage of an endotracheal tube, either for surgical access or to allow artificial ventilation to be performed. Removing the endotracheal tube at the end of the operation and re-establishing adequate spontaneous ventilation is often a problem. It is in this situation that the use of an iron lung can be of particular value for at least a short time until the patient is able to return to his normal methods of respiratory assistance.

The use of particular anaesthetic agents is less significant than the overall anaesthetic technique employed. In general, however, it is desirable and usually possible to avoid the use of muscle relaxant drugs. The polio muscle weakness usually renders them unnecessary, and it is usually impossible to reverse the action of these drugs completely and immediately. Residual effects tend to persist for some hours, and this can be a disadvantage for patients who need to use as much muscle strength as they possess in order to keep breathing adequately.

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PART II:

A Case for Re-evaluating Physical Therapy as a Viable Extended Treatment for Polio Individuals in the 1990's

Sandra Hughes Grinnell, Independent Medical Researcher

Continuing my research, I realized that I still needed to find a current article by a polio specialist actually advising the use of physical therapy specifically designed for tightness of muscles, so I could establish a pattern of advice going from the 1930's to the 1990's linking everything I had read together. That link appeared in the Fall (1990) issue of *Polio Network News*, in an article by **Dr. Thomas P. Anderson**, Spaulding Rehabilitation Hospital, Boston, entitled "Prescription For Pain" which states in part: "There are many people who feel that tightness plays a greater role in producing deformities after polio than weakness... Many people, including a lot of physicians, tend to overlook this. There is something that can be done about tightness and it is important not to forget that." He goes on to express disappointment that so few authors mentioned the recurrence of tightness. I share his disappointment especially because he goes on to say that many of us were told to do exercises in the early stages "not to get stronger, but to prevent the recurrence of tightness and that many of us were told to do these every day for the rest of our lives." Dr. Anderson, if you are reading this article, I think I can speak for many survivors when I say, "I wish you had been involved in my acute follow-up care, because I nor my parents were even given that advice, but thank you for restating it now."

I strongly suggest that you study his article along with the other materials I have suggested, and then, perhaps, you can begin to isolate your areas of tightness. After establishing your problem areas, you will be in a well-informed position to present a convincing case to your specialist for working with you to design a physical therapy program specifically for you with the goal being to achieve as much improvement as possible, and, then depending on your progress, have therapy treatments authorized to keep in reserve for "as needed maintenance." Ask your doctor to write to your insurance company citing recent articles like Dr. Thomas Anderson's.

In my case, even though I had my doctor's full support along with exceptional medical benefits, it still took additional effort on my part to convince them to cover my expenses which came to approximately \$5,000 for 80 treatments from April 1989 to May 1991. I kept forwarding copies to my insurance company of my physical therapist's notes documenting my steady

progress, along with names of medications I no longer needed and other related orthopaedic complications that I was actually reversing. I have been able to establish, so far, that my physical therapy has actually been a preventative form of medicine. To date, my insurance has paid 90% of my expenses for those treatments.

Barring unforeseen problems, I do not anticipate needing much help in the future. I feel so much more in control of my physical health again — needing less than an hour of exercise a day to maintain what initially took three to four hours a day, for months, to achieve. However, my doctor and I believe that my insurance carrier should continue to cover any treatments I may need now and in the future. If the insurance company is willing to certify future treatments on an "as needed" basis as a form of "extended maintenance care," thereby acknowledging that physical therapy has indeed been well-documented, in my case, to be the most useful and cost effective form of ongoing treatment for the late effects of acute polio; it may increase the chances that additional insurance companies will do the same for others. I will keep you posted through IPN of my status on this important issue.

4. COMBINING ADVICE AND CREATING A NEW STRATEGY — In the Winter (1991) edition of *Polio Network News*, **Dr. Jacquelin Perry** writes in an article entitled "Prescription For Weakness"; "An important point about muscle action is the fact that speed reduces muscle strength. ...so we recommend that polio survivors slow down... Give muscles time for repair and refueling in order to create force again... Polio individuals need to know their muscle strengths so they can plan safe levels of activity." Reading those words made me think back to 1984 when Dr. Perry examined me at the Polio Clinic in Downey, CA. It was shortly after that visit to the clinic that I came up with what I called my "swiss cheese" analogy with reference to finding the "invisible holes in our muscle strength" (see *Polio Network News*, Vol. 4, No. 4). I have expanded that analogy to include the importance of locating "invisible areas of muscle tightness." My doctor has documentation going back several years, in which he suggested a variety of traditional exercise programs, which consistently resulted in increased muscle tightness and painful spasms. In short, an

overall regression of stamina instead of progression. It was only in retrospect, after being diagnosed with post-polio syndrome, that those poor results year after year made any sense to him. In contrast, after two years of extended physical therapy, my doctor views the current improvement in my muscle strength, tone and alignment, as quite dramatic. We both agree that my overall physical fitness and flexibility is better than it was when I became his patient in 1975. We are therefore convinced that stretching of tight muscles, if done slowly, consistently and frequently — initially with the supervision and assistance of a well-trained physical therapist — is, in fact, in and of itself an incredibly productive form of exercise. For this reasons, I felt it was appropriate to expand my "swiss cheese" analogy for the benefit of other survivors and their doctors to include in their evaluation procedures. *(Remember — usually wherever you locate weak, stretched, lengthened muscle groups, there will be an opposing group of tight, strong, shortened muscles).*

I believe that if polio specialists were to combine Dr. Jacquelin Perry's advice on conserving muscle strength with Dr. Thomas Anderson's on stretching tight muscles, hopefully drawing on Florence Kendall's physical therapy work that I have cited in this article, they could together formulate a very balanced and conservative approach to physical therapy that is highly adaptable to individual needs and abilities of post-polio individuals. One possible strategy may be to have new post-polio physical therapy guidelines not unlike acute care guidelines with well-outlined charts and illustrations on muscle stretching protocol — preferably presented on video tape by polio specialists and therapists. These formal physical therapy guidelines would be an overview which any reputable family physician could prescribe and any well-trained physical therapist could implement right in the communities where the patients live. I, myself, did not have to go to a polio clinic for my treatments. Many, if not most, post-polio survivors do not live near polio specialists and/or clinics, so to be cost-effective to insurance companies, the more that can be implemented close to home, the better.

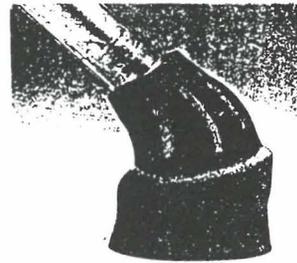
In cases where physical therapy is not available and/or affordable, much progress could be made right at home by beginning to initiate simple but effective physical and mental behavioral changes. In my case, for example, correcting my 1/4" leg length discrepancy was of equal importance to stretching tight muscles. These discrepancies have often been overlooked and/or minimized by the medical profession. After being evaluated by a physician, any reputable orthopaedic shoe store can make a quality shoe lift insert and/or alter the heels on existing shoes. In addition, they can custom fit you with shock absorbing heel pads to

cushion your spine when you walk. The deep breathing techniques referred to later in this article, for example, require no outside assistance and will improve your stamina. Perhaps, a video strictly for at home use which would make it possible for family members or friends to learn to safely assist a survivor with selected stretches. For example, stretching the pectoral minor muscles, per Florence Kendall's work, to improve breathing.

In retrospect, in my own case, after establishing my areas of tightness and corresponding weakness and

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A Case for Re-evaluating Physical Therapy *(continued from page 7)*

implementing a physical therapy plan of action, which included the use of a 1/4" heel lift, the next step, and the most important one, was to develop a long-term plan for conditioning my muscles to prevent further recurrence of tight muscles, thereby making changes permanent. The most efficient way for others to do this, if you have a professional therapist, is to take a very active role, on a mental level, in the physical therapy sessions that your doctor authorizes.

Often, your therapy is a "passive" experience for you physically, but think of each session as a class or seminar where you are going to *learn as much as you can about your body and how and why things work or do not work*. On your own, develop a heightened mental awareness of physical behaviors you do or not do throughout the day, which either increase or decrease your levels of pain. Then ask your therapist for suggestions to help you correct these behaviors. Finally, ask questions of your therapist as to what you need to do at home on an ongoing basis to make newly developed physical behavior patterns permanent. In my experience, highly skilled therapists spend more time and energy on a well-motivated patient, because it is more challenging to them and you reap the benefits. (Note: It is critical to a successful outcome, in the first two months at least, to relax and get plenty of rest in the 24 hours after treatments — making time to repeat your stretches. Trying to schedule a quick treatment on your lunch hour the way you perhaps used to schedule a tennis game, would be a waste of time and would probably do more harm than good. If you work full time, some kind of flexibility in your schedule will be needed. If necessary, use some vacation time to devote to your initial therapy treatments. If you are in a position to negotiate for a short medical leave of absence, do it!)

5. RE-MASTERING THE ART OF DEEP BREATHING — WE ALL CAN IMPROVE.

Since breathing capacity seems to be a great concern for many, there is a detailed outline including illustrations on page 30 of *Muscles: Testing and Function*, 1983, emphasizing the stretching of the pectoral muscles. It helps if you visualize these muscles as a thin membrane or sheath deep down in your chest cavity. They play an important role in breathing efficiency and more often than not, they are tightened by polio. With my physical therapist's assistance, I followed Florence Kendall's outlines on page 301 to the letter. Over time, emphasizing slowness and repetition, I experienced elimination of cramping in my chest, greatly increased breathing capacity, and an expanded level of physical endurance.

After you have increased your breathing capacity, you need to be further motivated to maintain it. The book, *Unlimited Power* has a terrific chapter which makes breathing correctly an art form you will want to master. If you do it correctly and routinely, it will change the biochemistry of your body as well as your mind. Finally, an excellent deep breathing, muscle stretching and conditioning video tape, entitled *Say Goodbye To Back Pain*, may help you. It was recommended to me in 1988 by a urologist and medical author by the name of Dr. Larrian Gillespie in Beverly Hills, CA. Normally one would expect to get a video like this from an orthopaedic specialist, but *Dr. Gillespie believes in the important inter-relationship of medical specialties*. She fervently believes that if a patient is motivated enough to use the video every day, as the exercises begin to improve abdominal muscle tone and stimulates increased blood circulation into the abdominal area, bladder function (as well as intestinal) will improve. (Many people with a history of polio have bladder and intestinal muscle tone problems in addition to orthopaedic problems all of their lives.) The video format is designed to help you to slow down when you stretch your muscles. By doing that, your mind will be able to focus on helping you to better isolate your areas of muscle tightness and opposing areas of weakness. Do not make the mistake of trying to do the routines from memory. I can tell you from experience you will tend to do each repetition much too fast, undermining the whole purpose. While it is true that some of you may not be able to do much more than the breathing exercises (which can be done sitting or lying on a bed), doing something is better than nothing. The video comes with a money back guarantee and is also available on audio tape. For more details you can call 800/826-8864 or write: Westwood Productions, 12121 Wilshire Blvd., Los Angeles, CA 90025. I am hopeful that perhaps one of you is in the video business and might consider using the *Say Goodbye To Back Pain* video format to create a tape exclusively made for post-polio individuals.

6. THE EMPOWERING STRENGTH IN BELIEVING THAT EVERYTHING HAPPENS FOR A REASON —

If you think everything has a reason, it will keep your mind open to ask "why?" and motivated to find the right answer. Always ask "why?" not so much as a patient with a limitation, but as a medical investigator with a challenge. A great illustration is a book by Meir Schneider, PhD, LMT, called *Self Healing, My Life and Vision*, Penguin Books, 1987. Born in Russia and raised in Israel, his book is available in four languages worldwide and has inspired countless numbers of people, including me, to realize that much of our healing ability has to come

within ourselves first. He is well known in holistic medical circles and has a Center for Self Healing, 1718 Taraval Rd., San Francisco, CA 94114 (415/665-9574). You can order the book directly from The Center, if you wish. Self healing for him appears to be a total commitment to highly personalized physical therapy programs based on the disability and/or illness. He was born blind in both eyes but by going through years of "physical therapy" for his eyes, he now has perfect vision. His book documents the details of his own case as well as patients with residuals of neuromuscular diseases, including polio. It is inspirational reading and made me realize that most of us could make significant progress which could indeed be maintained for the rest of our lives if we were totally committed! His book will help you set realistic and achievable goals. (I spoke with Dr. Schneider this summer. He told me he has a great interest in post-polio patients and has devoted a whole section of his soon to be released new book to the subject of treating post-polio syndrome.) Dr. Schneider recently forwarded copies of articles about himself, including interviews, which thoroughly document his accomplishments. Upon reading the articles, I realized that his total philosophy is a wonderful "mirrored" combination of all of the people I have cited in this article whose personal advice, articles, and books have shaped my remarkable progress to date. Video and audio tapes illustrating his therapy techniques for various illnesses are available at the address listed above. I hope that polio specialists worldwide will take a hard look at his impressive results and dedication to his work.

To get yourself in the right frame of mind, think back to how challenged and determined you felt during your acute care physical therapy program. Mentally put yourself there again and with the same spirit and enthusiasm you had then, *re-learn to pace yourself and re-educate yourself with new goals*. Carver Mead, a scientist at the California Institute of Technology in Pasadena, CA, was recently quoted to say, "The human brain is vastly more efficient than the best digital computer we have today." **Unlimited Power** will teach you how to access and use the full potential of your internal computer. You really can program yourself to make significant progress. Remember, also, that just as in weight reduction, you will reach plateaus and even though you are working very hard, nothing will happen. Then you will experience a seemingly sudden breakthrough which will be the encouragement you need. With enough breakthroughs you will never go back to your old behaviors, because you will know for a fact that your "sudden improvements" are no more "sudden" than your 30 year loss of strength was. You are simply now gradually replac-

ing old habits and behaviors that were dragging you down with ones that are quite literally lifting you up!

Maybe one of the reasons for post-polio syndrome in the grand scheme of things is, simply, that we still have an important contribution to make. After all, there are still children in other parts of the world facing life as a post-polio survivor someday. If we can convince the medical professionals and insurance companies that individualized physical therapy can be a preventative form of extended care, as well as being cost effective, think of all the individuals who will be able to conserve their energy much more efficiently than we have been able to do because of an expanded version of the acute care polio guidelines. (In order to be workable, these new guidelines would have to be flexible enough to allow for the medical variables which have accumulated over the past 30 years unique to each post-polio patient. I believe the results would be well worth the effort.)

In conclusion, whenever you start to procrastinate, think of the following — Life is not a dress rehearsal. Some of you may say, "Oh well, some people are just lucky." My answer to that is another quote from Anthony Robbins, "The meeting of preparation with opportunity generates the offspring we call luck." Based on that definition, I admit to being very lucky. So, why share my good luck with you now as I did in my first article in 1989, giving credit to all those who helped me along the way? Maybe another quote from Ben Johnson sums it up best when he says, "Everything that enlarges the sphere of human powers, that shows man he can do what he thought he could not do, is valuable."

NOTE: On July 12, 1991, my doctor made a formal, written request to my medical insurance company for "ongoing physical therapy on a maintenance basis." Even though I have not needed any treatments for several months, on July 31, 1991, my insurance carrier certified an additional six treatments "to be used on an 'as needed' basis for the next year subject to continued review" for certifying additional treatments in the future. The diagnosis reads *Late Effects Acute Polio*. Although it is a very limited number of treatments, it is certainly a breakthrough decision for an insurance company to make. Prior to this extension, they have approved and paid for approximately 80 treatments since April of 1989, so I am not complaining! I hope it gives others reading this article additional encouragement to try to get the help you need.

Sandra Hughes Grinnell, B.A., graduated from the University of California, Santa Barbara, with a major in sociology and a minor in psychology with emphasis on behavior modification. She and her husband, William, a senior environmental specialist for the Southern California Edison Co., have resided in Southern California for over 20 years. Medical professionals and survivors may write to Sandra with questions or comments c/o International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110.

Post-Polio Bibliography

"Late effects of paralytic poliomyelitis in Olmsted County, Minnesota," A.J. Windebank, MRCP(UK); W.J. Litchy, MD; J.R. Daube, MD; L.T. Kurland, MDF, DrPH; M.B. Codd, MB; and R. Iverson, RN. *Neurology*, Vol. 41, No. 4, pp. 501-507, April, 1991.

Recognizing that most reports of the late effects of polio come from post-polio clinic populations, and not knowing whether these can be generalized to the total population at risk, the researchers utilized the centralized records linkage system at the Mayo Clinic: "Every patient-physician contact is recorded with a coded diagnosis for automated retrieval. This includes referrals and local patients. For the population of Olmstead County, Minnesota, diagnostic information is available on all residents. This provided the opportunity to study a population of subjects who had paralytic polio and whose acute illness was well documented. No other similar data resources exist. Using this population, we planned to identify the prevalence of specific symptoms many years after acute polio." The results of a "detailed historical, functional, psychological, clinical, and electrophysiologic evaluation" of 50 subjects are described.

"Intrathecal Immune Response in Patients with the Post-Polio Syndrome," Mohammad K. Sharief, MB, ChB, MPhil, Romain Hentges, MD, and Maria Ciardi, MD, *The New England Journal of Medicine*, Volume 325, Number 11, pp 749.55, September 12, 1991.

This study examined "the intrathecal immune response to poliovirus and local synthesis of interleukin-2 and soluble interleukin-2 receptors by the central nervous system in 36 patients with the post-polio syndrome and 67 control patients." The article concludes "... intrathecal immune response against poliovirus is present in many patients with the post-polio syndrome."

In the Discussion section the researchers comment, "Our finding that poliovirus specific oligoclonal IgM bands were found only in some patients with the post-polio syndrome suggests that there is an immune response to antigenic stimulation in the central nervous system, probably by poliovirus." In addition, they state, "Longitudinal follow-up of patients with post-polio syndrome and therapeutic trials with antiviral agents will allow our hypothesis to be tested further."

ORTHOPEDICS TO FEATURE POST-POLIO SYNDROME

The November 1991 and December 1991 issues of *Orthopedics* will feature articles on post-polio syndrome. The issues were edited by **Richard L. Bruno, PhD**, of the Kessler Institute for Rehabilitation in New Jersey.

To order your copy(ies), contact Slack, Inc., 6900 Grove Road, Thorofare, NJ 08086-9447 (609/848-1000). Each issue costs \$8 until January 1 when the price will increase to \$15 each. International orders, including Canada, cost \$16 each and will increase to \$30 each after January 1.

Results of Texas Tech University Gastrointestinal Survey

Sinn Anuras, MD, and Terri Bozeman, RN, reported the results of their G.I. survey at the Second Texas-Oklahoma Post-Polio Symposium, September 21-22, 1991, in Wichita Falls, TX. They have compiled statistics on the incidence of several G.I. problems — swallowing, heartburn, nausea, vomiting, bloating, diarrhea, constipation, and intestinal pseudo-obstruction.

Dr. Anuras, Director, Division of Gastroenterology, Department of Internal Medicine, Texas Tech University, Health Sciences Center, Lubbock, TX 79430 (806/743-3130), stated that polio survivors could assist their research by sending small bowel and colon tissue to them. If you undergo surgery, and it is feasible, please send "full thickness biopsy of the small bowel or colon in formalin" to the above address. If you and your surgeon desire more details, contact Dr. Anuras.

The GI survey sparked the interest of Texas Tech researchers concerning urological problems of polio survivors. **Jonathan S. Vordermark, MD, FACS, FAAP**, Division of Urology, Texas Tech Health Sciences Center, Medical Office Plaza, 3502 9th St., Suite 260, Lubbock, TX 79415, conducted a survey of randomly selected polio survivors and asked them to provide information on the acute episode of polio and the nature of new or late-onset neurological symptoms that could be attributed to PPS. He reported the data from 173 questionnaires.

Readers may purchase the notebook from this symposium, which includes the reports of Dr. Anuras and Dr. Vordermark, while the supply lasts. Send \$10 postpaid to **Barbara Miller**, 4503 Allison, Wichita Falls, TX 76308 USA.

Influenza Vaccine

Influenza vaccine is strongly recommended for any person over 6 months of age who — because of age or underlying medical condition — is at increased risk for complications of influenza. Health-care workers and others (including household members) in close contact with high-risk persons should also be vaccinated. In addition, influenza vaccine may be given to any person who wishes to reduce the chance of becoming infected with influenza. Influenza vaccine is made from highly purified, egg-grown viruses that have been rendered noninfectious (inactivated). Therefore, the vaccine cannot cause influenza.

(Editor's Note: Consult your primary care physician for details and advice.)

SOURCE: Morbidity and Mortality Weekly Report, May 24, 1991 Vol.40/No. RR-6

Social Security Announces New Toll-Free '800' Number

Social Security's toll free telephone number is changing. Beginning October 1, 1991, the number to call is **1-800-SSA-1213 (1-800-772-1213)**.

Potpourri

POST-POLIO SYNDROME INCLUDED IN CURRICULUM

Dorothy Woods Smith, MA, MS, RN, of Maine reports that she authored the section on post-polio syndrome in the *Second Edition (1991) of the National Association of Orthopaedic Nurses Core Curriculum for Orthopaedic Nursing*. In the future, orthopaedic nurses receiving certification will have knowledge of post-polio syndrome.

FROM THE FIBROMYALGIA (FM) NETWORK

Some symptoms of post-polio syndrome are similar to FM. Franklin Lue, M.D. and Harvey Moldofsky, M.D. investigated the possibility that post-polio syndrome is another manifestation of FM in polio survivors.

Most patients with FM (and Chronic Fatigue Immune Dysfunction Syndrome) have a characteristic sleep disorder (alpha-EEG) in which slow-wave sleep is disturbed. Therefore, Drs. Lue and Moldofsky sleep tested and examined 47 polio survivors. The outcome of this study revealed that polio survivors did not have tender points of the alpha-

EEG sleep disorder, implying that they represented a distinctly different pain-fatigue syndrome.

INFORMATION ON RSDS

Evelyn M. Porter from Cambridge Springs, PA, whose husband is a polio survivor, informed us that a booklet (\$0.50) entitled *Reflex Sympathetic Dystrophy Syndrome (RSDS): Help Us Stop The Pain* is available from Reflex Sympathetic Dystrophy Syndrome Association (RSDSA), P.O. Box 821, Haddonfield, NJ 03033 USA. They will also supply information on physician seminars and patient services.

Post-Polio Directory 1992

Before the next newsletter, we will be mailing forms to all clinics, health professionals, and support group leaders listed in the 1991 Post-Polio Directory. We will ask you to make any corrections in your listing and confirm your willingness "to be there" for polio survivors by returning the form. Please make every effort to return the form by the stated deadline. Additions to the directory are welcome. Contact International Polio Network, 5100 Oakland Avenue, # 206, St. Louis, MO 63110 USA (314/534-0475).

Post-Polio Directory 1991

Please add the following:

HEALTH PROFESSIONAL

Thomas Chr. Lehmann, MD
Buergienweg 5
Ittigen CH - 3063
Switzerland

CLINICS

Shepherd Spinal Center
Post-Polio Outpatient Clinic
Donald P. Leslie, MD
Naomi Abel, MD
2020 Peachtree Rd., N.W.
Atlanta, GA 30309
404/350-7355
800/548-6651

University of Rochester
Medical Center
Kathy Scherer, RN
Strong Memorial Hospital
Outpatient Neurology
Box 673
601 Elmwood Ave.
Rochester, NY 14642
716/275-4423

Charlotte Rehabilitation
Hospital
William L. Bockenek, MD
1100 Blythe Blvd.
Charlotte, NC 28203
704/355-4300

Stewart Rehab Center
Connie Hector, RPT
McKay-Dee Hospital
3939 Harrison Rd.
Ogden, UT 84409
801/625-2080

Our Lady of Lourdes
Donald G. Dicken, MD
516 W. Margaret, #8
Pasco, WA 99301
509/545-0414

St. Elizabeth Medical Center
Marie K. Boudreaux, MD
110 S. 9th Ave.
Yakima, WA 98902
509/575-5003

Theda Clark Regional
Medical Center
Post-Polio Clinic
Andrew Haig, MD
130 Second St.
Neenah, WI 54956
414/729-3015

SUPPORT GROUPS

Mt. Diablo Post-Polio Network
Beverly Borzy
Mary Ellen Brown
P.O. Box 968
Danville, CA 94526-2519
510/837-7639

Post-Polio SG of Orange County
Priscilla Hiers
18552 Cork St.
Fountain Valley, CA 92708
714/968-1675

Post-Polio Syndrome SG
Easter Seal/Del-Mar Inc.
Richard C. Thamm, Pres.
1211 Bruce Rd.
Wilmington, DE 19803
302/764-1714

Can Do!
Judy Huff
Route 5, Box 302
Ft. Scott, KS 66701

Post-Polio SG of Sandusky
Easter Seal of Erie County
Sue Donner
912 Perry St.
Sandusky, OH 44870
419/626-8447

Post-Polio SG
Easter Seal Society
Janet Hughes
175 St. Francis Av.
Tiffin, OH 44883
418/447-9815

South Texas Organization of
Polio Survivors (S.T.O.P.S.)
Sandy Paulich
11013 White Sands
Live Oaks, TX 78233-3054

Please make the following changes:

SUPPORT GROUPS

Easter Seal for Ind. Living
Rosie Zappo
61 Corporate Circle
New Castle, DE 19720

Polio SG of Northwestern
University
Elizabeth Reeves
215 East Chestnut, # 1601
Chicago, IL 60611
312/664-6071

Post-Polio SG of Portage Co.
1429 Tallmadge Rd.
Kent, OH 44240

S.N.A.P.S.
Sara Gardner
Las Vegas, NV 89180

Rose Kratz
1126 W. Casino Rd. #27
206/290-9402
Marilyn Boyd
206/355-4249
Everett, WA 98204

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Resources Available

The Late Effects of Polio — Information for Health Care Providers and a Practical Approach to the Late Effects of Polio, both by Charlotte Leboeuf, are available from **Post-Polio Support Group of South Australia, Inc.**, c/o The Neurological Resource Centre of South Australia, Inc., 37 Woodville Road, Woodville, South Australia 5011 (08 268 6222). The centre will bill you for postage.

International Polio Network recently received their first copy of *Effets A Long Terme de la Poliomyelite Manuel pour les Medecins et les Post Polios*, the French translation of its *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*. The translation and publication was done by **Association des Paralyses de France**, which added a chapter on the polio experience in France.

Poliomyelitis anterior acuta-die spatfolgen, insbesondere die chronische Unterbeatmung is a booklet about the late effects of poliomyelitis written in German. Authors **Paul Walther, MD**, head of the polio center at the Insel Spital in Berne, Switzerland, for 34 years and **Thomas Christian Lehmann, MD**, polio survivor and head of Department of Rehabilitation, have combined their long-term experiences with the information in the medical literature. The book, completed in February 1991, addresses the problems of polio survivors in the Swiss community in an interdisciplinary manner. For a copy, send \$18 to Thomas Chr. Lehmann, Buerglenweg 5, CH-3063, Ittigen, Switzerland.

Proceedings from *Staying In The Workplace*, a one day symposium sponsored by the **Toronto Peel Post Polio Committee**, are available. To order, please send \$17.00 to Helen Murchie, Treasurer, Attn. Shirley Teolis, Ontario March of Dimes, 60 Overlea Blvd., Toronto, Ontario, M4H 1B6, Canada.

Sinemet-Neuroline is a service for neurologists sponsored by Merck & Company. Sinemet-Neuroline located at 1800 Robert Fulton Drive, Reston, VA 22051-9963 can be reached at 800/345-6676. Neurologists must enroll through their Merck representatives to receive a bi-monthly newsletter and to have access to a free literature search service. Share this information with your neurologist to insure that he/she has the latest medical literature on polio's late effects.

CALENDAR

The Late Effects of Polio, BEH Auditorium, Mercy Hospital, Des Moines, IA, March 27-28, 1992. Contact: Norma Cornelius, Iowa Polio Survivors Group, 1319 Johnson Ave., Ames, IA 50010 USA (515/232-7237).

You're Not Alone is a video showing the value of self-help groups. The program follows the progress of a mother with post-partum depression and a workman dealing with brain injury. This 17-minute video is available from Suncoast Media, Inc., 11801-6 28th Street N., St. Petersburg, FL 33716 (1-800-899-1008). Suncoast Media also now distributes the video Post-Polio Syndrome which was taped in connection with the First Pacific Northwest Regional Polio Conference, Nov. 2-5, 1989 sponsored by the Post-Polio Awareness & Support Society of British Columbia.

"Gone Fishin" for Fun and Fitness is a new videocassette featuring fishermen with a disability using the adaptive equipment available on today's market. Shot in ten locations, the \$29.95 video features 14 people with various disabilities, including polio. For more information contact: J.L. Pachner, LTD, 13 Viadi Nola, Laguna Niguel, CA 92677 (714/363-9831).

Insurance and Alternatives for Uninsurables (ISBN 0-922802-01-7) by Roger A. Kessinger, a life and health insurance agent, was copyrighted in 1989 and sells for \$24.95. The 260-page book contains: States with High Risk Health Insurance Pools; Foundations that Give Grants to Individuals for Medical Care; Medical Associations that Give Free Medical Care; Associations that Provide Medical Assistance, Support Groups, Counseling, or Information; Insurance Terms and Policy Provisions that Uninsurables Need to Know; Why Banks May be the Best Place to Buy Insurance; Fraternal Organizations that Give Free Medical Care; Government Benefits; How and Where to Apply for Disability Medicaid, Medicare, Veterans Benefits, and Workers Compensation; Impaired Risk Brokers and Agents; Laws that Protect Uninsurables; Insurance Companies that Insure Impaired Risk Cases.

For more information contact: Kessinger Publishing Company, Box 160, Kila, MT 59920 USA (800/255-5384).

