POLIO NETWORK NEWS

SPRING 1993 ♦ VOL. 9, NO. 2

International Polio Network

PART II

Becoming an Intelligent Consumer of Physical Therapy Services

Marianne T. Weiss, P.T., Canton, Ohio

The following completes the comprehensive article begun in the Winter issue of *Polio Network News* (Vol. 9, No. 1).

Marianne T. Weiss, P.T., received her Bachelor of Science degree in physical therapy from The Ohio State University in 1977.

Marianne's interest in polio began when she was 11 after watching *Sunrise at Campobello*, a movie about Franklin D. Roosevelt. She consequently read every book available about FDR and polio, and she decided at age 14 to be a physical therapist. A family friend, who had polio, was the first person she had ever met with a disability. She credits him with teaching her how to react and interact with people with disabilities.

In 1981, while the director of the physical therapist assistant program at Stark Technical College in Canton, Ohio, she invited the local symphony director, a polio survivor, to speak to her students about life with a disability. He became her first patient with post-polio related problems.

Today, Marianne is in private practice and can be contacted at Community Physical Therapy, 4176 Holiday St., N.W., Canton, OH 44718-2532 (216/493-7700).

Marianne's article is based on her years of experience and on both the medical and lay literature. For a copy of her bibliography, send a business-size envelope with 52¢ postage to International Polio Network.

Strength

EVALUATION. Close, specific testing of the strength of each muscle is important. Gross testing of muscle groups is not appropriate in polio survivors. Specific testing is necessary because a hallmark of polio was the fact that it skipped about the body in seemingly random fashion, affecting parts of a muscle here and parts of a muscle there, sparing parts of muscle here and sparing parts of muscles there. I know of no other testing protocol other than that advocated by Florence P. Kendall, P.T., that is adequate to test polio survivors. Survivors and professionals may be referred to the 1983 third edition of Kendall's book, *Muscle Testing and Function*, which she co-authored with her daughter, Elizabeth Kendall McCreary. Her protocol is one of manual muscle testing. Testing with Kendall's

Rancho Later Life Study

A two-day conference, Meeting the Challenges of Aging with a Disability: Lessons Learned from Post-Polio and Stroke, was held in Long Beach, CA, March, 1993. The conference was the culmination of a five-year project (*Polio Network News*, Vol. 6, No. 3) funded by the National Institute on Disability and Rehabilitation Research (NIDRR), Department of Education.

Most persons with a physical disability, like the population at large, can now be expected to live a longer life. However, as they age, many start to experience the onset of new health problems and secondary complications which threaten to further erode their independence and well being. Among those individuals who are vulnerable to these "secondary disabilities" are the survivors of the two leading causes of paralysis in the United States today — polio and stroke.

The five-year Later Life Study conducted at the Rehabilitation Research and Training Center on Aging at Rancho Los Amigos Medical Center involved individuals 50 years or older, and compared persons with early onset of polio and spinal injury, to those with a stroke occurring after age 50, and non-disabled controls.

A total of 265 individuals, ranging in age from 50 to 88, participated in the study. These included 120 polio survivors (not all of whom were considered to have post-polio syndrome), 60 stroke survivors, and 60 non-disabled controls, plus an additional 25 persons with spinal cord injury who were not reported on during the conference. Each participant received a comprehensive medical exam, including laboratory analysis of EKG, blood chemistry, and bone density testing for osteoporosis; a physical therapy evaluation; a psychological evaluation by a clinical psychologist, and a personal history interview by a medical sociologist.

Although not all of the data had been analyzed by the time of the conference, principal investigator Margaret L. Campbell, PhD, co-principal investigators Bryan Kemp, PhD, and Kenneth Brummel-Smith, MD, presented some preliminary information at the meeting. The final report will be completed by August 15, 1993.

The Rancho Later Life Study concluded, in part, the following:

Polio survivors experiencing the greatest problem dealing with post-polio issues are those in the "sandwich" generation — individuals in their early fifties

Becoming an Intelligent Consumer, Part II

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methods is easier if the patient is clothed in a manner to allow the evaluator to see the muscles being tested.

Many people think that testing should be done only with sophisticated exercise equipment that is found in sports therapy clinics or in clinics that specialize in the rehabilitation of injured workers. I feel that most polio survivors cannot be adequately tested by machines such as this, due to using abnormal substitutive movements that can potentially cause harm in the presence of significantly compromised strength. Again, I will emphasize that for individual, specific muscle testing, I know of no other protocol other than that advocated by Florence Kendall.

The only adaptation to Mrs. Kendall's techniques that I advocate, if possible, is using a hand-held dynamometer during the testing. If the P.T. has access to such a device and is skilled in using it, the dynamometer readings can add valuable information to a manual muscle test. For example, one muscle that grades 3+ on a 1 to 5 scale might be capable of producing only 6 pounds of force (as measured on a dynamometer) while another muscle grading 3+/5 might be capable of producing as much as 12 pounds of force.

A word of explanation regarding the grading of muscles is appropriate. The Kendalls advocate documenting muscle grades by the use of percentages, i.e., 90-100%, etc., in conjunction with the old terms used by Dr. Robert Lovett in the early decades of this century, which were, normal/good/fair, etc. Another method for labeling muscle grades is using numerals 1 to 5. I have adopted this 1 to 5 grading system as being the easiest way to document on a record the value of the strength of a given muscle.

Given the above set of numbers, on a 1 to 5 scale, a grade of 3 would be approximately 50%. However, it is important for health professionals and polio survivors to understand the concepts documented in 1961 by Beasely. He found that polio survivors' muscle grades do not correspond with the above ratios. An abbreviated version of Dr. Beasely's study is listed below.

Muscle Grade in Polio Survivors	% of Functioning Muscle Fibers in Muscles Having This Muscle Grade
5	53.5% to 100%
4	42.5%
3	9.1%
2	2.5%
1	1.0%

Given Dr. Beasely's study, it is important for polio survivors to understand that even though their best muscles may grade in the vicinity of 3+ on the 5-point strength scale, their percentage of normal muscle strength may only be 10 to 20%.

Another factor important to consider in strength testing is endurance. If the survivors can tolerate it, I usu-

ally have them perform 3 to 4 trials of a given motion before recording the final grade. Not infrequently, I find that the first trial is significantly better than the third or fourth trial. If this is the case, I will record the value on the first trial and the value on the third or fourth trial and label them as such. It is important to recognize that a survivor may be able to put forth effort with one or two repetitions, but may not be able to duplicate that effort with sustained repetitions. In fact, in some cases a survivor may be unable to even initiate a movement after 3 or 4 attempted repetitions.

TREATMENT. Given all the factors above, there is a fair amount of controversy in the literature regarding the utility of strengthening programs in polio survivors. Some sources say that even in polio muscles grading 4/5, only an 11% gain in strength is possible with a concerted exercise program, and that this cannot be sustained over time. The implication is that if grade 4 muscles react this poorly, then certainly strengthening for weaker muscles is also of questionable value or even contraindicated. There is also definite danger in over-exercise. At least four researchers have shown increased weakness in response to nonspecific, intensive exercise.

My personal experience and recommendations are as follows:

- "Strengthening" exercise seems most useful in assisting survivors to learn more normal movement patterns. It is doubtful that true strengthening occurs, but patients seem better able to use their available strength as a result of exercising.
- ♦ All "strengthening" programs should be implemented only in the context of a person's cardiopulmonary function.
- ♦ If a person cannot perform a given motion without substituting abnormal movement patterns, it is rarely useful to attempt to "strengthen" muscles performing that motion. Doing so would only further stress overworked muscles and further reinforce abnormal movement patterns. This sets a person up for worsening pain syndrome.
- ♦ If the muscles of a given extremity grade 3+/5 or better for 3 to 4 repetitions without substitution patterns, they may respond to a low-level "strengthening" program. Characteristics of this program might include:
- —0-3 pounds of free weight resistance;
- —hold count of 2-5 seconds followed by 2-5 seconds' rest which allows for adequate rotation of muscle fiber firing without fatigue;
- -2-5 repetitions performed 2-3 times per week;
- use of abdominal-diaphragmatic breathing with sustained exhalation as a means of reducing blood pressure elevation with exercise and activating abdominals to stabilize the trunk pelvis during exercise.

- ♦ If the muscles of a given extremity grade 3+/5 or better without substitution patterns BUT the extremity has compensated for years for a significantly weaker contralateral extremity, in general, it should not be stressed by further exercise. This is especially true in the upper extremities. Attempts should be made, however, to teach normalization of movement patterns, e.g., normal scapulohumeral rhythm, pelvic-trunk diassociation, etc.
- ♦ Isometric exercise may be useful for muscles grading 2-3/5 to promote circulation in that body part. Isometrics may also help retain some joint stability in body parts with this much weakness.
- ♦ Low level aerobics may be useful for people
- —without severe heart/lung problems;
- —whose arms grade 3+/5 or greater or whose legs grade 3+/5 or greater;
- -having adequate trunk strength.

Lap swimming, walking in a pool, or biking with the arms or legs seem to be best tolerated as aerobic activities. In general, 15 to 20 minutes total aerobics (including warm-up/cool down) is the maximum recommended. Minimal resistance for biking is recommended at speeds no greater than 30 MPH. Walking on dry ground is not as often recommended because of the trauma produced by abnormalities in walking patterns.

Survivors should recognize that, in general, it is considered that a muscle must have a grade of at least 3+/5 to function in A.D.L. without external support (bracing/orthotics). If a muscle grades less than 3+/5, using that muscle during A.D.L. without orthotic support puts that body part in great risk for developing joint instability and pain. If a person desires to avoid pain and further dysfunction, muscles with this degree of weakness should be properly splinted or braced.

Sometimes physicians or survivors are reluctant to recommend or accept bracing because they fear that, "whatever strength is there will decline." While this may be true to some extent, isometric exercise or simple anti-gravity exercise without weighted resistance will go a long way towards retaining the existing strength, even in the presence of orthotic support. At all costs, remember that the trade-off for not using adequate orthotic support in the presence of significant weakness is further pain and dysfunction.

Posture

EVALUATION. As with gross strength testing, gross posture assessment yields little useful information. How-ever, using the results of a very specific posture and strength assessment can be the basis for important recommendations for assistive devices.

Posture assessment should encompass evaluation of bone angulation and length and joint abnormality, along with the more traditional concept of posture that includes alignment of the major body parts with one another. It is important to evaluate both sitting and standing posture. It is important to make some conjecture on the posture evaluation as to whether a specific posture deviation is a fixed, permanent type of deformity or a flexible one that might be possible to change with appropriate intervention.

TREATMENT. Addressing posture can be very helpful in minimizing or preventing pain and increasing endurance for sitting/standing/walking. Sometimes simple instructions in posture correction techniques, both in sitting and standing, are helpful. Other times, selective strengthening exercises are helpful in normalizing posture.

In the presence of more pronounced weakness, foot, trunk, or extremity orthoses may be necessary. Correction of leg length (even slight differences) may make the difference between the presence of pain and being pain free.

Bed Mobility and Transfers

EVALUATION AND TREATMENT. A P.T. should look closely at a survivor's ability to move in bed. The P.T. can then use this as a teaching time for offering suggestions as to positioning for comfort to minimize

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International Polio Network

5100 Oakland Avenue, #206 St. Louis, MO 63110-1406 U.S.A. 314/534-0475 314/534-5070 Fax



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EDITOR/EXECUTIVE DIRECTOR ♦ Joan L. Headley

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pain-producing or skin-irritating stress on body parts.

Evaluating the survivor's ability to rise from a chair and to sit from standing can yield valuable information about how a person is able to functionally use his/her strength. This information can be used to point out painful biomechanic stresses on the body that result from the methods used and to suggest possible alternative movement patterns or assistive devices that may be helpful (e.g., lift chair, tub seat, etc.).

Gait Testing

EVALUATION. If polio survivors are able to walk, it is important to evaluate them on level surfaces, inclines, curbs, and stairs if possible. Some clinics are able to videotape walking performance. This is helpful so the survivors can see for themselves the abnormalities that the P.T. is identifying on the evaluation.

Evaluation of a person's gait is often traumatic for poliosurvivors. I have found frequently that polio survivors have been reluctant to even watch themselves in mirrors. The survivors are surprised and sometimes dismayed at the deficient quality of their gait. Sometimes it is the evaluation of gait that is the deciding factor in a polio survivor's mind as to whether or not to accept assistance from a P.T. or whether or not to consider positively suggestions for use of assistive devices.

The biomechanic stress resulting on the survivor's body from abnormal gait must be pointed out. For example:

- the stress on the back during a profound forward/ sideways/backward leaning of the trunk;
- the repetitive stress on the joints and muscles of the legs that results from severe "back knee";
- trauma to the arms resulting from using crutches, etc.

The P.T. may also point out how a person may be compensating with one muscle for weakness in another muscle. Correlating the strength and ROM evaluations with the gait evaluation is helpful.

If survivors are unable to walk, the P.T. should assess their ability to use wheelchairs, etc. Again, observation on more than flat surfaces is helpful.

TREATMENT. If most leg muscles grade 3+/5 or greater, low-level exercise (see above) and instruction in gait normalization may be all that is necessary. For significantly weaker muscles, orthotic devices or canes/crutches, etc., might be recommended. Often upper body weakness or pain is so pronounced that use of crutches, etc. must be discouraged. In these cases, encouraging the use of power wheelchairs or scooters may be necessary.

Skin

EVALUATION. A P.T. should do at least a gross assessment of the easily visible skin. The P.T. should comment on the presence of swelling, skin color, temperature, and quality (scaliness, moist, dry, thin, etc.). The P.T. should pay special attention to any areas of skin in contact with braces, special shoes, etc. If the survivor sits the majority of the time, the P.T. may wish to request permission to look at the skin over the buttocks.

TREATMENT. The P.T. should instruct survivors in measures for controlling swelling, skin care, turning schedules, skin inspection, etc. In some cases, the use of pneumatic pumps or pressure gradient garments (Jobst, etc.) are helpful in controlling swelling or improving skin quality.

Assessment of Appliances

EVALUATION AND TREATMENT. Survivors should bring all special equipment that they have used in the preceding five years to the evaluation, if possible. The P.T. should observe the survivor's ability to use this equipment and comment on whether modification of the equipment may be helpful or whether alternative devices may be necessary.

Pain

EVALUATION AND TREATMENT. The P.T. should evaluate the presence of pain and use the results of the rest of the evaluation to determine contributing factors to the pain. Sometimes correction of posture, movement patterns, ROM, etc. can decrease pain. Other times use of orthotic devices or reduction of ambulation time will reduce pain.

If polio survivors suffer acute sprains, etc., often treatment with traditional physical therapy physical agents (hot packs, cold packs, ultrasound, etc.) is helpful. However, chronic pain in polio survivors often responds best to special massage techniques such as craniosacral therapy, myofascial release, soft tissue mobilization, etc. The survivor should request if the P.T. is trained in these pain-relief massage techniques. If the evaluating P.T. is unskilled in these techniques and chronic pain is a significant problem, the survivor should request a referral to a P.T. who does perform these techniques.

Summary

Physical therapists can offer valuable comprehensive evaluative services to polio survivors. Based on the results of the evaluation, treatment plans may be developed and implemented that may significantly improve the quality of life for polio survivors. Physical therapists can also serve as educators of both polio survivors and their referring physicians.



St. Louis, MO 63110-1406 USA 5100 Oakland Ave.. #206 31+/53+-5070 Fax 314/534-0475

Did you have polio?

¿ Ha tenido Jud. la polio?

Est-ce que vous avez jamais eu la polio?

Waren sie an Poliomyelitis erkrankt?

(or know someone who did?)

(¿o conoce Ud. a alguien que la ha tenido?)

(ou connaissez-vous quelqu'un qui l'ait eue?

(oder kennen Sie jemanden, der Kinderlähmung hatte?)

For more information about the late effects of polio, contact:

Rancho Later Life Study Continued from page 1

with responsibilities of launching children, aging parents, and careers. This finding reinforces the idea that a "life course" perspective of disability will increase our understanding of how disability affects individuals and families.

The health evaluation found few statistically significant differences between the polio group and the control group, including no higher rates of obesity, cholesterol (actually lower), EKG changes (actually fewer), blood pressure, and glucose levels. Age-associated diseases do not appear to be more common in polio survivors.

The study did show a higher rate of hypothyroidism in polio survivors. Routine health maintenance should probably include thyroid screening, particularly if survivors are experiencing symptoms such as fatigue, which, in some cases, could be alleviated if the hypothyroidism was treated.

For purposes of the study, depression was defined in two ways: One, by using clinical diagnostic criteria which included profound altered mood, six-to-eight symptoms (e.g. fatigue, thinking or sleep disturbances), and behavioral disturbances. The second definition of depression was based on clinically significant symptoms only and is less severe.

Overall findings indicate that polio survivors are somewhat less depressed than the non-disabled control group, although the mean differences were not statistically significant. However, among polio survivors, women reported significantly higher depression scores than men (although still within normal limits), and one group of survivors, those in their early fifties who experienced acute polio after 1940, had scores consistent with clinically significant symptoms.

Funding was obtained to give one copy of the conference proceedings to each support group. They are being revised and will be available by July 1, 1993. Additional copies, as well as tapes from the conference, can be ordered. Contact: Millie Sealana, Associate Training Director, Rehabilitation Research and Training Center on Aging, Rancho Los Amigos Medical Center, University of Southern California, 7066 Consuelo St., Downey, CA, 90242 USA (310/940-7402/8953).

The Center has been funded for another five years starting August, 1993. It will continue its focus on aging and polio with an expanded sample of over 450 individuals, which will include a random sample of 60 individuals from the first five-year study, 300 from the Rancho post-polio clinic, and another 100 from the local community.



Polio survivors are, of course, as susceptible to stroke as anyone else.

STROKE SYMPTOMS

The most common warning of stroke is a TIA (transient ischemic attack). It is a disturbance of blood supply to a localized area of the brain. Complete and spontaneous recovery usually happens in 24 hours or less. You should suspect that you or a member of your family has had a TIA if one of the following happens, lasting perhaps one to 15 minutes and leaving no visible after-effects:

- Sudden weakness, paralysis or numbness of the face, arm or leg, especially on only one side of the body
- · Difficulty in speaking or swallowing
- Difficulty understanding spoken or written words
- · Mental confusion
- · Changes in personality
- · Double vision, clearing after a short time
- Temporary dimness or loss of vision, particularly in one eye
- Dizziness
- · Falling for no apparent reason
- Unexplained headaches or a change in the pattern of headaches

Stroke Association of Southern California, 2001 South Barrington Ave., #308, Los Angeles, CA 90025 USA.

IN MEMORIAM

Albert B. Sabin 1906-1993



Live every day as if it were your last,

Live every day as if you would live forever.

—ALBERT B. SABIN, M.D.

We Need to Speak to Be Heard

Joan L. Headley

Recently, I was invited to another polio-related meeting — my 30th plus in the last five and a half years. At each meeting I speak and I listen. I speak about our organization's 40-year history, or the power of networking, or the role of support groups and self help. Sometimes, I set the stage for the professionals who will follow me; other times I wrap up after the professionals, putting things in perspective for my fellow polio survivors.

And I listen. Listening, many times, is my favorite task. Questions, comments, and expressed frustrations cue me in on what needs to be the next feature in *Polio Network News*. Listening helps me formulate opinions and consensus about us as a group and our needs.

The emphasis may change from meeting to meeting, but three issues are consistently on the minds of polio survivors — access to health care, funding for research, and need for increased awareness.

Access to Health Care

The Task Force on National Health Care Reform is scheduled to release its plan soon. As polio survivors we need to scrutinize the plan for its provisions regarding people with disabilities: What provisions are made for pre-existing disease? For prescription drugs? For accessing specialists experienced in treating secondary disability, or post-polio problems? For rehabilitation services, including durable medical equipment such as braces, wheelchairs, portable ventilators? For inclusion of long term care/attendant care/PAS as an alternative to institutionalization? For changes in Medicare/Medicaid? For consumer participation in decisions, particularly quality of life decisions?

Some of the aforementioned are considered to be expensive and ultimately may be judged too expensive. We as polio survivors from our acute polio experiences know the benefits and ultimate cost savings of rehabilitation and assistive devices. A great many of us have worked, paid taxes, raised families, contributed to our communities, and led a quality life with our braces, from our wheelchairs, and on our ventilators. Without comprehensive coverage which recognizes people with disabilities, and their chronic health conditions, our ability to live independent lives, and fully participate in the community, will be in jeopardy.

This Task Force needs to hear from us — write to Hillary Rodham Clinton, The White House, 1600 Pennsylvania Ave., Washington, DC 20500; so must our legislators who will vote on the plan — United States Senate, Washington, DC 20510, and U.S. House of Representatives, Washington, DC 20515. Letters of concern should also be addressed to Donna Shalala, Secretary of Health and Human Services, 200 Independence Ave., SW, Washington, DC 20201. HCFA, the Health Care Financing Administration, is an agency of the Department of Health and Human Services and

directs the Medicare and Medicaid programs — overseeing what these programs will and will not cover.

FUNDING FOR RESEARCH

The National Polio Research Coalition, a joint effort of International Polio Network and The Polio Society, distributed 30,000 pre-printed postcards through the Network's support group system, and to readers of *Polio Network News* who previously requested to be on the Coalition list. [To be added now, send your name and address to International Polio Network (IPN), 5100 Oakland Ave., #206, St. Louis, MO 63110-1406.] The colorful cards contained a message to senators and representatives requesting their "support for post-polio research by the National Institute of Neurological Disorders and Stroke and the National Center for Medical Rehabilitation Research." Funding decisions are considered by members of the following committees:

Senate Appropriations Committee: Sub-committee on Labor, HHS, and Education

Democrats: Robert C. Byrd (WV), Chairman; Daniel K. Inouye (HI); Ernest F. Hollings (SC); Dale Bumpers (AR); Tom Harkin (IA); Henry Reid (NV); Herb Kohl (WI); Patty Murray (WA)

Republicans: Mark O. Hatfield (OR), Ranking Member; Ted Stevens (AK); Thad Cochran (MS); Arlen Specter (PA); Slade Gorton (WA); Connie Mack (FL); Conrad Burns (MT)

House Appropriations Committee: Sub-committee on Labor, HHS, and Education

Democrats: William Natcher (KY), Chairman; Neal Smith (IA); David R. Obey (WI); Louis Stokes (OH); Steny Hoyer (MD); Nancy Pelosi (CA); Nita Lowey (NY); Jose Serrano (NY); Rosa DeLauro (CT)

Republicans: Bill Young (FL); John Porter (IL); Helen Bentley (MD); Henry Bonilla (TX)

Your legislators and the above members of the Subcommittees may be contacted regarding funding for research by calling the Capitol switchboard, 202/224-3121, or by writing to them at the U.S. Senate, Washington, DC 20510, or the U.S. House of Representatives, Washington, DC 20515.

AWARENESS

At the request of many, International Polio Network has created an awareness poster for general distribution (the centerfold of this issue). Additional copies are available for a donation of \$1 each as long as the supply lasts.

Our attempt to establish National Polio Awareness Week through Congress in the recent past has not met with success. This year, at the suggestion of several congressmen, we wrote directly to the White House who, in turn, felt it best we work through Congress. Many legislators do not involve themselves with commemoratives because of staff time and the cost to the taxpayer. Also, some legislators report that they "do not hear from polio survivors."

I hear from polio survivors all the time and, in the name of IPN, speak for you. It is my job. However, as a polio survivor, I would write to the powers-that-be anyway, because I prefer speaking for myself. My goal in sharing these thoughts is to cause you to speak along with me.

Serving Survivors on Ventilators

In the '50s, polio survivors who were left with breathing complications were living in hospital wards or at home with respiratory equipment paid for by the National Foundation for Infantile Paralysis (March of Dimes). After the development of the polio vaccines, funding for polio survivors was greatly reduced by the March of Dimes. Much of the original equipment was still available, however, and individuals still living in respiratory wards were sent home with this equipment, which included chest cuirasses, rocking beds, pneumobelts, and iron lungs.

In the '60s LIFECARE (see next column), a manufacturer of ventilatory equipment, purchased the wide variety of negative and positive pressure ventilator devices from the March of Dimes (MOD).

Today, LIFECARE still services polio survivors using the original equipment and has an agreement with the MOD to assist polio survivors if (1) the diagnosis on the prescription for ventilator equipment mentions polio, (2) the ventilator equipment and accessories are obtained through LIFECARE.

If a survivor has no insurance and is not eligible for Medicare or Medicaid, MOD will pay for all of the equipment, but will only approve the earlier types of equipment such as blowers, Bantams, iron lungs, rocking beds, exsufflation belts, 170Cs, chest shells, pulmo-wraps, and PVVs. They will not pay for the PLV-100, PLV-102, NU-MO suits, or Porta-Lungs.

If a survivor has insurance or is eligible for Medicare or Medicaid, the equipment must be billed through the insurance carrier, Medicare, or Medicaid first, and MOD will pay for the 20% not covered. In this case, all types of ventilators are covered including the PLV-100 and PLV-102. However, the survivor is responsible for any deductibles.

Many polio survivors have routinely changed equipment as new technology becomes available, and have actively contributed to the development of the newer equipment available today.

G.I.N.I. publishes *I.V.U.N. News*, a biannual newsletter which links ventilator users with each other and health professionals interested in home mechanical ventilation. Articles are written by individuals with experience of living at home with a ventilator and by knowledgeable health professionals. The newsletter can provide important information to polio survivors possibly needing ventilatory assistance due to underventilation. *I.V.U.N. News* subscription rates are \$8 for ventilator users/survivors, \$20 for others. Canada, Mexico, overseas surface add \$2.00. Overseas air, add \$4.00. G.I.N.I. also distributes a *Directory of Sources for Ventilation Face Masks*. It is available for \$2.50. Canada, Mexico, and overseas add \$1.50.



LIFECARE® International, Inc.

Geoffrey Waters

655 Aspen Ridge Drive ♦ Lafayette, CO 80026-9341 303/666-9234 ♦ FAX 303/666-0415

LIFECARE Europe GmbH, Downey Wright, RRT Postfach 20, Hauptstrasse 60, D-8031 Seefeld 2, Germany

49/8152-70728 ♦ FAX 49/8152-78199

U.S. DISTRICT OFFICES Phone: 800/669-9234

Atlanta,

Kathy Westerman, CRTT 2220 Northwest Pkwy.,

Marietta, GA 30067 Tel: 404/952-5559 FAX: 404/952-5899

Baltimore, Joe Golden, RRT 7048F Golden Ring Rd. Baltimore, MD 21237

Tel: 410/574-2880 FAX: 410/391-4407

Boston

267 Boston Rd., #16 North Billerica, MA 01862

Tel: 508/670-5759 FAX: 508/670-5764

Chicago, Joy Mannella, RRT 318 St. Paul Blvd. Carol Stream, IL 60188

Tel: 708/653-4477 FAX: 708/653-5265

Cleveland, Bob Miller, RRT 925-C Basset Rd. Westlake, OH 44145 Tel: 216/892-1480

FAX: 216/892-3984

Denver, Scott St. John, RRT 4301 S. Federal Blvd., #114 Englewood, CO 80110 Tel: 303/797-8418 FAX: 303/730-7808

Detroit, Gary Kopczyk, RRT 11902-B Farmington Rd. Livonia, MI 48150

Tel: 313/458-5170 FAX: 313/458-5175

Houston,

Robert Garcia, RRT 8058 El Rio Houston, TX 77054 Tel: 713/747-8006

FAX: 713/741-5448

Kansas City, Jeff Davis, RRT 108 N.W. Parkway Riverside, MO 64150 Tel: 816/741-7667

FAX: 816/741-4853

Los Angeles, Mark Hicks, RRT 8210 Katella Ave., #B Stanton, CA 90680

Tel: 714/895-1781 FAX: 714/897-6293

Minneapolis,

Barb Platten, CRTT 1230 Eagan Industrial Rd., #175

Eagan, MN 55121 Tel: 612/452-5229 FAX: 612/452-5314

New Orleans,

Coy Marshall, CRTT 1525 River Oaks Rd. East, #E Harahan, LA 70123

Tel: 504/733-1911 FAX: 504/736-9231

New York,

Steve Savino, RRT 135 Raritan Center Parkway Edison, NJ 08817

Edison, NJ 08817 Tel: 908/417-2222 FAX: 908/417-2227

Oakland, Jay Nash, RCP 4861 Sunrise Drive, #106 Martinez, CA 94553 Tel: 510/370-0500 FAX: 510/370-1575

Phoenix, Tony Rodela, RRT 3822 E. University Dr., #4 Phoenix, AZ 85304 Tel: 602/470-1288 FAX: 602/470-1292

San Diego,

Kelly Smith, CRTT 9520 Padget Street, #107 San Diego, CA 92126 Tel: 619/549-7871 FAX: 619/549-3579

Seattle, Al Letterer, RRT 11915 124th Ave., N.E. Kirkland, WA 98034 Tel: 206/823-5677 FAX: 206/823-8430

Tampa, Peg Warren, CRTT 5808 Breckenridge Pkwy., #F Tampa, FL 33610

Tel: 813/621-0114 FAX: 813/623-6935

Gazette International Networking Institute (G.I.N.I.)

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CALENDAR

- ♦ Post-Polio Management Update III, Auditorium at McKennan Hospital, Sioux Falls, SD, June 12, 1993. Contact: Tri-State Polio Survivors, Inc., P.O. Box 88941, Western Mall Station, Sioux Falls, SD 57105-8941, or Kim Husby, 605/338-2894.
- ♦ Be Your Own Medical Advocate, Holiday Inn Denver Southeast, Aurora, CO, September 10-12, 1993. Contact: Julia Beems, 303/233-1666, or Bev Holst, 303/423-1179, or 800/875-4732.
- ♦ Copenhagen Post-Polio Conference, Copenhagen, Denmark, September 23-24, 1993. Contact: Gertie E. Larsen, PTU (National Society of Polio and Accident Victims), Tuborgvej 5, DK-2900, Hellerup, Denmark (45 3162 9000).
- ♦ Post-Polio Consumer Forum sponsored by The American Academy of Physical Medicine and Rehabilitation, November 2, 1993, Tuesday, 2:00 p.m. to 5:00 p.m., Fontainebleau Hotel, Miami, FL. More information as it becomes available.
- ♦ Sixth International Post-Polio and Independent Living Conference, St. Louis Marriott Pavilion Hotel, St. Louis, MO, June 16-19, 1994. Contact Joan L. Headley, International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110-1406 USA (314/534-0475 or FAX 314/534-5070).

New Polio Clinics Open

Macon Rehabilitation Center, 3330 Northside Dr., Macon, GA 31210 recently opened a post-polio clinic. The team consists of Michael Shoffner, MD, a neurologist, and a physical therapist. Other services are available on an as-needed basis. Call 912/471-2140 or 800/491-3550.

Florida Hospital, 5165 Adanson St., Orlando, FL 32804, will open a post-polio clinic in May. Mitchell Freed, MD, a physiatrist, is in charge. Call 407/895-7600.

* * *

Polio survivors, health professionals, and anyone interested in becoming part of a post-polio support group in Volusia and Flagler counties Florida, please call Barbara Goldstein (904/676-2435).



1748 Independence Blvd., Suite B1 Sarasota, FL 34234 (800/96-HOVER)



"As a private school administrator, I am required to be very active, but as a post-polio survivor I experience a significant level of pain in my affected leg, back, and shoulders. I must limit my physical activity when possible, and Hoveround has allowed me to extend my work life.

"More maneuverable than a wheelchair, I can get around our campus easily, getting in and out of classrooms, as well as small office areas.

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"I can get where I need to go with the Hoveround."

-STEVEN J. PONCHOT