INTERNATIONAL POLIO NETWORK

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TIPS ON SHOPPING FOR A SCOOTER

By Doug Harrison, Houston, Texas

WHEEL DRIVES

Front wheel drive scooters are small and tend to be less expensive than rear wheel drive scooters. They can turn in a very tight circle making them suitable for getting around inside in tight spaces. Front wheel drive scooters are easy to maneuver indoors or outdoors on any hard, level surface. However, maneuvering is more difficult in thick carpet, on steep inclines, or outside in gravel and grass.

Most rear wheel drive scooters are larger than front wheel drive units and not suitable for small spaces. Rear wheel drive scooters have great traction and will drive through grass, dirt and gravel, or up and down hills.

DRIVE MECHANISMS

All front wheel drive scooters have either a belt and chain, or two belts which turn the front wheel. There are four different systems used for rear wheel drive scooters; 1) A belt and chain; 2) A sealed gear box and a chain; 3) A sealed gear box and a belt; and 4) A completely sealed direct gear drive.

The direct gear drive is much smoother, quieter, more durable, and requires much less maintenance than the other systems. Direct drive scooters are available from Alpha Mobility, Amigo, Electric Mobility, Leisure Lift Ortho-Kinetics, and Shoprider.

FRAMES

Scooters usually weigh about 100-150 pounds and most people are unable to lift a 100 pound scooter into their car. Scooters with modular frames come apart into four or five pieces making it easier to put a scooter in the car trunk. Some models are much easier than others to take apart and put back together.

One piece frames will fit into a standard size car trunk, however, they are very heavy. Electric lifts are available to help load a scooter into a trunk.

SEATS

There are a wide variety of seats available. All provide different levels of comfort and support. Some scooters come with very plain seats but can usually be upgraded to larger, more plush seats when ordering.

Most of the large manufacturers offer several types of adaptive seating such "Jay" seat cushions, sheepskin

seat covers, high back seats, seat belts, and adjustable seats which can be custom molded. Additionally, most rehabilitation centers can design and build a complete custom seating system if that is needed.

Some seats have solid molded frames, while others have a back which folds down. The folding seats are much easier to transport.

All scooters come with 360 degree swivel seats making it easier to get on and off, and with seat lock mechanisms keeping the swivel seat from turning while getting on and off and driving. Some seats can swivel freely unless you apply the seat lock. Others are always locked in position unless you pull the release. Some scooters are now available with electronic seat locks allowing the seat to be locked and unlocked at the touch of a button, instead of manually pulling or pushing a lever.

ARMRESTS

Armrests provide additional stability and comfort while on the scooter. Scooters come with flip up armrests; with fixed arms; with no arms. Scooter armrests can be upgraded when ordering.

BATTERY CHARGERS

All scooters have a battery charger. There are three types: external, on-board, and built-in.

An external charger is a separate box which has two cords — one to be plugged into the scooter, and one to be plugged into an electrical outlet. An external charger must be transported separately when traveling.

An on-board charger is similar to the external charger, except it is smaller, and there is a place on the scooter for the charger box to sit. Some have a mounting bracket to hold the charger in place. An on-board charger makes it easier to travel because there is not another piece of equipment to worry about.

A built-in charger is permanently mounted inside the base of the scooter. All that is required to charge up the scooter is an electrical outlet. Some built in chargers require a special extension cord and some have the charging cord built into the base. If you travel with this scooter, there are NO additional parts to worry about.

TIPS ON SHOPPING FOR A SCOOTER

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TILLERS

The tiller is the handle bar that is used to steer the scooter. Some tillers are very plain and simple, while others are very fancy with horns, fuel gauges, speed controls, and on/off switches. Some tillers can be adjusted forward and backward making it easier to get on the scooter, offering more comfort for arms, and assistance in transporting the scooter. Some tillers can also be telescoped up and down.

PERSONAL PREFERENCE

Once you have decided on wheel drive, drive mechanism, and frame, the rest is up to personal preference what kind of seat, how big should it be, how big should the wheels be, what color, which is most comfortable? Personal preference will determine whether a sports car, the Cadillac, or the economy version is purchased.

LIFTS

Electric lifts help put the scooter into the car, truck, or van without depending on anyone else.

There may also be a financial incentive to purchasing a lift. <u>Some</u> states refund the sales tax paid on the vehicle. For more expensive cars, the sales tax refund may be several hundred dollars more than the cost of the lift. For more information about this refund in Texas, call the Texas State Comptroller's office toll free at 800-252-5555. Others should contact their state comptroller or department of revenue.

Also, if you are purchasing a new vehicle to carry your scooter, you may be eligible for assistance from the car manufacturer. Ford pays up to \$750; Chrysler pays up to \$1500; GM pays up to \$1000; and Saturn pays up to \$1000. The rebate may be used to cover the lift and the installation.

There are several different types of lifts.

Some lifts fit in your car trunk. A trunk lift does require removal of the seat and removal or tilting of the tiller. Next a cable is attached to the scooter. The lift, which is connected to the car battery, lifts the scooter up which swings around and is lowered into the trunk.

Rear exterior lifts attach to the back of the car, on a regular receiver hitch. The scooter is driven onto the lift's platform. When a button is pressed, the lift picks up your entire scooter and secures it.

Lifts for mini-vans are becoming extremely popular. The mini-van lift picks up the entire scooter and swings it into the rear of the van. There is no need to remove anything. A mini-van lift can allow someone with extremely limited mobility to load and unload a scooter without any assistance. There are also lifts

made specifically for vans, hatchbacks, suburbans, pick-up trucks, and station wagons.

INSURANCE AND MEDICARE

Insurance may pay for the whole thing, but it depends on what type of insurance you have. Medicare may pay for the whole thing if Medicare's requirements are met. Usually, lifts are not covered by insurance or Medicare, but check into the possible auto tax refund.

Tips Regarding Medicare ...

Doug Harrison distributes the information below to his potential customers. The information also applies to other dealers in the United States. One exception could be that other dealers may or may not elect to take assignment.

WILL MEDICARE APPROVE A SCOOTER FOR YOU?

In a nutshell: Medicare will buy you a scooter if you <u>must</u> have one to be able to get around <u>inside</u> your home.

Medicare will not pay for equipment used by someone in a nursing home. Medicare will not pay for a lift to put your scooter in a vehicle. Medicare refers to all electric wheelchairs and scooters as power operated vehicles (POV).

International Polio Network

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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.

ISSUED QUARTERLY

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According to Medicare's Coverage Issues Manual 60-5 and 60-9: A POV is covered when ALL of the following criteria are met:

- 1. The patient's condition is such that a wheelchair is required for the patient to get around in the home,
- 2. The patient is unable to operate a manual wheel-chair,
- 3. The patient is capable of safely operating the controls for the POV, and
- 4. The patient can transfer safely in and out of the POV and has adequate trunk stability to be able to safely ride in the POV.

Very important quote from Medicare ... "Most POV's are ordered for patients who are capable of ambulation within the home but require a power vehicle for movement outside the home. POV's will be denied as not medically necessary in these circumstances."

How Much WILL MEDICARE PAY?

Answer for Texas: \$1468.04, NEW; \$1101.02, USED. Answer for other states in Region C: Each state is different but the range is \$1689.82 to \$1987.79 NEW; \$1336.29 to \$1572.11 USED. The range will vary for Regions A, B, and D. See below for the listing of states in each Region. Your physician will know the exact figures for your Region and state.

Medicare will pay 80% of the allowable amount, or 80% of the actual cost of the scooter, whichever is less. You or your secondary insurance will be responsible for the payment of the remaining 20% or 20% of the actual cost of the scooter, whichever is less.

PURCHASING YOUR SCOOTER

There are two ways to purchase a scooter and file for Medicare coverage.

Non-Assigned You may select any scooter, regardless of price. You pay for the scooter, in full, and take delivery of your scooter immediately (Delivery time for custom ordered scooters is 2-4 weeks). The SCOOTER Store will then file a Medicare claim for you. Medicare will reimburse you directly for the covered amount when and if your claim is approved.

Assigned You may only select from a limited number of scooters, based upon the price of the scooter. You will be required to pay any deductible or co-payment in advance. However, you still take delivery of your scooter immediately. Medicare will reimburse The SCOOTER Store directly for the balance. Although The SCOOTER Store is not a "participating provider," we can submit Medicare claims on assignment on a case by case basis. The SCOOTER Store will file an assigned claim for you ONLY if you have a Confirmation Letter with a Prior Approval Number. (For more info see the discussion about assigned claims at the end of this article.)

THE FIVE ITEMS REQUIRED TO FILE A CLAIM

1. Certificate of Medical Necessity (CMN) — DMERC 07. (Not required if you have a prior approval number.) The CMN must be filled in by a specialist in physical medicine, orthopedic surgery, neurology, or rheumatology.

Another very important quote from Medicare "A POV is usually covered only if it is ordered by a physician who is one of the following specialties: Physical Medicine, Orthopedic Surgery, Neurology, or Rheumatology. When such a specialist is not reasonably accessible, e.g. more than one day's round trip from the beneficiary's home, or the patient's condition precludes such travel, a prescription from the beneficiary's physician may be acceptable. When the ordering physician is in a specialty other than the four listed in coverage rules, additional documentation must be sent in with the claim which clearly describes the special curcumstances."

- 2. **Insurance claim form HCFA 1500.** You must fill out the 1500 Health Insurance Claim Form. Only the top part of the form through box 14, needs to be filled out by you. Have your doctor fill in boxes 17, 17A, and 21. The SCOOTER Store will fill out the rest.
- 3. **Doctor's written order.** You must have a "note-pad" prescription from your doctor. This prescription must be on a piece of paper that has your doctor's name printed on it (just like the pads of paper they use for drug prescriptions). The note-pad prescription should read something comparable to: "Three wheel electric scooter," NOT "electric wheelchair."

Scooters can be reimbursed by Medicare only if the doctor has furnished The SCOOTER Store a written order for the scooter, before you take delivery of the scooter.

- 4. **Copy of Your Medicare Card.** You will need to provide The SCOOTER Store a copy of your Medicare card.
- 5. **Copy of your receipt.** You must enclose a receipt for the scooter showing the make and model.

Be sure to make copies of everything for your records. It is always possible that your claim may get lost in the mail, or may get lost by Medicare.

A paper claim (without prior approval) will take 6 to 8 weeks to process. A claim that requires additional reviews, appeals, and fair hearings will take considerably longer.

PRIOR AUTHORIZATION FOR MEDICARE

Very simply stated, your doctor <u>or his/her employee</u> can call Medicare (DMERC for your region), get an approval number, and you can go get your scooter.

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REGION C DMERC (Durable Medical Equipment Regional Carriers) covers Texas, Puerto Rico, Virgin Islands, AL, AR, CO, FL, GA, KY, LA, MS, NM, NC, SC, OK, TN.

REGION A DMERC covers CT, DE, ME, MA, NH, NJ, NY, PA, RI, VT.

REGION B DMERC covers DC, IL, IN, MD, MI, MN, OH, VA, WV, WI.

REGION D DMERC covers AK, AZ, CA, Guam, HI, ID, IA, KS, MO, MT, NE, NV, ND, OR, SD, UT, WA, WY.

According to Medicare, prior authorization should be obtained by your doctor before you get a scooter. All that your doctor or his/her employee has to do is call the Prior Authorization phone number. Medicare will usually give their decision to the doctor's office during that same phone call. If the prior authorization is approved the doctor's office will be given a prior approval number.

Your doctor or his/her employee will be asked all of the questions on the CMN form (DMERC 07.01). Their answers will determine whether or not you are approved for a scooter. The answers required for approval are discussed in Section #1 above: Will Medicare approve a scooter for you? Your doctor will be required to certify that all answers are true, accurate, and complete. Falsification, omission, or concealment of material fact may subject him/her to civil or criminal liability.

Obtaining a prior approval number means that you may elect to have The SCOOTER Store submit an assigned claim for you. However, it will also benefit you on a non-assigned claim.

1. On a non-assigned claim the advantage of Prior Approval is that you are almost guaranteed to have your claim approved.

POST-POLIO BIBLIOGRAPHY

"Coping With the Late Effects: Differences
Between Depressed and Nondepressed Polio
Survivors." Denise Tate, PhD; Ned Kirsch, PhD;
Frederick Maynard, MD; Christopher Peterson,
PhD; Martin Forchheimer, MPP; Allison (Sunny)
Roller; Nancy Hansen, PhD. American Journal of
Physical Medicine & Rehabilitation, February, 1994,
Volume 73, No. 1, pp. 27-35.

This study examined differences between depressed and nondepressed individuals with a history of paralytic poliomyelitis in terms of demographics, health status and coping strategies. Only 15.8% of the sample (116) had scores indicating depression and elevated distress.

2. The SCOOTER Store will file an assigned claim for you ONLY if you have received a letter from Medicare confirming your Prior Approval Number.

ASSIGNED CLAIMS

On an assigned claim, your selection of scooters will be limited. The limit is based upon the allowable amount set by Medicare. The SCOOTER Store is prohibited by federal law to collect more than the allowable amount on any assigned claim. Please do not ask us to file a claim for a scooter that is over the federally set allowable. (We don't like small rooms with bars, and we don't like to eat bread and water!!)

The scooters which are available to you on an assigned Medicare claim are any new scooter under the allowable amount for your state (\$1835.05 in Texas) or any used scooter under the allowable amount for your state (\$1376.28 in Texas). Out of 200 plus scooters, there are only five or six which fall within this price range.

What about getting other scooters on assignment? If you are interested in a scooter that is not listed above it is probably due to the price of the scooter. SINCE MEDICARE IS ONLY APPROVING YOUR SCOOTER FOR USE INSIDE YOUR HOME, THE ALLOWABLE AMOUNT IS SET TO COVER A SMALL INDOOR SCOOTER. If your assigned claim is approved for any of the above scooters, Medicare will buy THAT scooter for you. If you want a more expensive scooter, you will have to file a non-assigned claim.

WILL MEDICARE PAY FOR REPAIRS?

YES! — if and only if Medicare purchased the scooter for you.

If Medicare <u>did not</u> buy your scooter, they will not pay for any repairs.

You will be required to pay for the repairs at the time you pick up your scooter. The SCOOTER Store will file your claim for you. You will be reimbursed directly from Medicare, if your claim is approved. For your claim to be approved, you must have documentation showing that Medicare bought your scooter, and a current prescription from an approved doctor.

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DOUG HARRISON is the owner/operator of two scooter stores in Texas. For further information, contact Doug at The Scooter Store, 1937 IH 35 E, Suite 100, New Braunfels, TX 78130 (800/828-1736, 210/620-4425) or 7613 Katy Freeway, Suite C, Houston, TX 77024 (800/777-1736, 713/682-1444).

WE WANT YOUR OPINION ON OUR DISABILITY PROGRAM, SAYS SSA!

By Douglas M. Smith, Physicians' Disability Services, Inc.

"Reengineering" the disability program is high priority for 1994 and 1995, according to Social Security Administration commissioner Shirley S. Chater. Ms. Chater announced the reforms in hearings held October 28, 1993 by the Social Security Subcommittee, House Ways and Means Committee. An SSA team will furnish Ms. Chater reengineering recommendations in March 1994, and the agency plans pilot projects for 1995. How far will disability program changes go? SSA is "fundamentally rethinking and radically redesigning the work process," says an SSA newsletter. "[T]he winds of change are reaching hurricane force ..."

SSA says it wants opinions from the public on the disability program. But the agency talked first to its own employees, interest groups, and "focus groups." The focus groups included selected members of the public and met privately in six cities. They were organized and managed by a private contractor the SSA press office would not identify.

What questions should public comments address? According to the Social Security Forum, monthly newsletter of the National Organization of Social Security Claimants' Representatives, SSA wants to know the following:

- 1. What aspects of the disability process work well today?
- 2. What aspects are most difficult for claimants?
- 3.Do claimants need assistance? How much, what kind?
- 4. Can claimants supply medical information for claims (instead of SSA getting it)? If so, how can SSA help them?
- 5. Are there ways that medical providers can aid their patients in filing claims? If so, how?
- 6. Should the SSA decision maker see the claimant and the claimant see the decision maker? If so, for all claims?

We urge people who have claimed disability benefits to register their opinions with the Hon. Shirley S. Chater, Commissioner, SSA, 800 Altmeyer Building, 6401 Security Boulevard, Baltimore, MD 21235. And with us, Physicians' Disability Services, Inc. ("PDS"), P.O. Box 827, Arnold, Maryland 21012. PDS will send questionnaires for its survey to people calling 410/974-1111 or sending a fax to 410/263-6636. We also will send a summary of our results.

SOCIAL SECURITY TOLL FREE TELEPHONE NUMBER: 800/772-1213

To receive individual copies of any of the publications below, call the 800 number above between 7:00 a.m. and 7:00 p.m. business days.

Program Booklets

Understanding Social Security (No. 05-10024: Conprendiendo El Seguro Social (No. 05-10924) Disability (No. 05-10029): Incapacidad (No. 05-10929) Medicare (No. 05-10043): Seguro De Salud (No. 05-10943) SSI (No. 05-11000): Seguridad de Ingreso (No. 05-11090)

Factsheets

Reviewing Your Disability (No. 05-10068)
The Appeals Process (No. 05-10041): El Proceso
De Apelacion (No. 05-10941)

Specialty Pamphlets

Benefits For People With Disabilities Who Work (No. 05-11002)

Working While Disabled — A Guide to Plans for Achieving Self-Support While Receiving SSI (No. 04-11017): Trabajando Mientras Esta Incapacitado — Una Guia Para Un Plan de Ayuda A Si Solo Mientras Recibe Seguridad de Ingreso Suplemental (No. 05-10997)

Right to Representation ...

It has been the Social Security Administration's longstanding practice to notify claimants and beneficiaries of their right to be represented at each step during an administrative review of their case. However, recent amendments to the Social Security Act have made it a legal requirement that claimants be notified of the options for obtaining a representative when they appeal a decision. So, when Social Security notifies a claimant that his or her claim has been denied, the agency will also provide a list of attorney referral and legal services organizations as well as community organizations that may be able to provide representatives who are not attorneys.

A Reminder ...

The listing in Social Security Administration's Program Operations Manual System (POMS) relevant to polio survivors with post-polio problems is under Evaluation of Late Effects of Poliomyelitis (not Post-Polio Syndrome). It is found under Part 04 Section DI 24580.010. ■

THE GLOBAL ERADICATION OF POLIO — A PROGRESS REPORT

By Robert A. Keegan, Public Health Advisor, Centers for Disease Control and Prevention

In 1988, The World Health Assembly resolved to eradicate polio by the year 2000. This ongoing global initiative for the eradication of polio offers the greatest hope for the elimination of this once common disease, and the post-polio syndrome which frequently follows years later. This report summarizes global progress towards eradication and outlines the challenges which remain before the goal can be reached.

Extraordinary progress has already been achieved in the Western Hemisphere. In 1985, the Pan American Health Organization (PAHO) resolved to eradicate polio in the Western Hemisphere by 1990. An average of about 1000 cases were reported each year in the early 1980s in Latin American countries. Under the leadership of Dr. Ciro de Quadros, PAHO mobilized support for the governments of its member states and from several donor agencies including Rotary International, U.S. Agency for International Development, Inter-American Development Bank, UNICEF, and the Canadian Public Health Association. PAHO assisted the polio-endemic countries of Latin America to strengthen surveillance for suspected polio cases, to develop a laboratory network for virologic confirmation of cases, and to conduct highly organized and effective national immunization days and other supplemental immunization efforts for all children under five years old. These strategies appear to have been successful. The last case of confirmed polio in all of the Americas occurred in Peru in 1991.

Similar progress is now occurring in the countries of East Asia. In 1988, the Western Pacific Region of the World Health Organization (WHO) adopted a resolution to eradicate polio in all 35 countries of the region by 1995. Rapid progress has been made using the same basic strategies developed by PAHO. National immunization days were held in Vietnam, Laos, Philippines and China. More than 400,000 volunteers were mobilized to assist in the immunization days in the Philippines alone. In China, more than 100 mil-

ROBERT A. KEEGAN currently serves as the operations manager for CDC's polio eradication activities, coordinating CDC's efforts to provide technical, programmatic, and laboratory assistance to the World Health Organization and polioendemic countries.

Mr. Keegan will speak at the Sixth International Post-Polio and Independent Living Conference in St. Louis, MO, June 16-19, 1994.

lion children received a dose of oral polio vaccine in each of two immunization days held in December 1993 and January 1994. This immense immunization effort in China was considered by many experts to be the largest single public health event ever conducted. China has been involved in supplemental polio vaccination activities on an increasing scale since 1991. The efforts of the polio-endemic countries have yielded a sharp decline in the number of reported polio cases in the East Asia region, from almost 6,000 in 1990 to just 2,087 in 1992. Preliminary information suggests that the total for 1993 will be well below 1000.

Although the industrialized countries of Western Europe had been free of polio for several years, an outbreak of polio in the Netherlands in late 1992 provided a reminder that no single country can be safe from polio until all countries are free of polio. A breakdown in the health care infrastructure of the new republics of the former Soviet Union has resulted in an upsurge in 1993 in the number of polio cases in Uzbekistan (68 cases), Azerbaijan (64 cases), Tadjikistan (14 cases), the Ukraine (5 cases), and several other republics. Coordinated assistance from developed countries and international organizations will be essential to stabilizing the routine immunization programs and implementing the special activities needed to eradicate polio.

Perhaps the greatest challenges to polio eradication are on the Indian sub-continent and in Africa. In some countries routine coverage with the recommended three doses of oral polio vaccine is as low as nine percent. The lack of strong programs for routine immunizations make it difficult to implement the special strategies for polio eradication recommended by WHO. In these situations, health experts are trying to improve basic immunization programs while simultaneously initiating the special activities needed to eradicate polio.

Countries with civil unrest present special problems. Recent fighting in Burundi led to the death of a number of key health workers and resulted in a massive disruption of immunization services. However, examples of solutions to these problems suggest that with adequate political commitment, these problems can be overcome. Despite civil unrest on the island of Mindanao in the Philippines, a special "ceasefire for children" was held so that national immunization day activities could occur unimpeded by the threat of violence.

With the leadership of the world Health Organization, and support from UNICEF, Rotary International, the

Centers for Disease Control and Prevention and other organizations, polio eradication activities are now being planned or initiated in virtually all polioendemic countries including India, Pakistan, Indonesia, and countries in sub-Saharan Africa.

The global eradication of polio is feasible with existing vaccines and technical resources. The only significant obstacle which remains is to obtain adequate commitment from all government and public health leaders worldwide to this worthy goal and to dedicate the funds necessary to get the job done.

The smallpox eradication effort led by WHO in the 1960s and 1970s offers clear examples of the financial and humanitarian benefits which accrue to the world community following the total eradication of a disease. Since the last case of smallpox was detected in 1977, more than \$2 billion has been saved in the United States alone. More importantly, thousands of deaths and millions of cases of a disfiguring disease are avoided each year.

Achievement of the global eradication of polio will offer similar benefits to mankind. In the United States alone, more than \$230 million will be saved annually in polio vaccine and administration costs when the global eradication of polio is achieved and polio vaccinations can be stopped. Similar benefits can be expected in other industrialized countries. The humanitarian benefits of the elimination of this once dreaded disease, and ultimately of post-polio syndrome, are incalculable.

Rotary International has played a key role in supporting the polio eradication initiative. Rotarians around the world have raised more than \$240 million to buy polio vaccine and to pay for other costs of this program. Just as importantly, Rotary has mobilized volunteers to provide manpower and community support for eradication activities.

Despite these impressive efforts, much more remains to be done. Broad-based financial and political support is needed. WHO estimates that \$50-75 million is needed annually during the next 5 years for polio eradication activities in addition to the approximately \$25 million already available from Rotary International, the governments of Japan, Australia, and the United States, and other donors.

WHAT CAN YOU DO TO ENSURE THAT POLIO ERADICATION IS ACHIEVED?

- Persuade government leaders that despite many demands on their countries' resources, polio eradication is feasible, cost-effective, and once achieved, would free up resources to help meet other demands.
- Contact corporations and businesses about underwriting the cost of vaccines, cold-chain equipment, technical experts for disease surveillance and laboratories, laboratory supplies, transportation of supplies, and promotional efforts.

- Urge nongovernmental organizations and religious leaders of all denominations to involve their members in supporting the eradication effort.
- Contact newspapers and television and radio stations expressing your concern about polio and the need to follow through on the initial successes of the polio eradication program.

Polio survivors know more than anyone what a remarkable gift polio eradication would be for the children of the 21st Century. ■

Potpourri

International Exchange of Experts and Information in Rehabilitation (IEEIR) has awarded an overseas fellowship for the purpose of collecting data about polio and post-polio in China with a particular focus on the concept of aging with a disability, and seeking and understanding cultural knowledge of disability and rehabilitation in order to further understand "the invisibility" of Asian-Americans with disabilities to Haiou Yang, Ph.D., and Joanne Yamada, M.Ed., of the Pacific Basin Rehabilitation Research and Training Center of Honolulu, Hawaii.



Mobility International USA (MIUSA) is soliciting information concerning participation of women with disabilities in international development activities.

Of the estimated 250 million women in the world today who are considered disabled, approximately 3/4 live in "developing" countries. International development programs, however, even those specifically focusing on women, have rarely addressed the needs of women with disabilities, nor have they included women with disabilities in community development ventures. It is time for women in development organizations to actively recruit and involve women with disabilities, to interrupt the cycle that keeps them stigmatized and isolated in their communities.

MIUSA will publish a booklet, Including Women with Disabilities in Development Projects, which will be available in the fall of 1994, with translations in French and Spanish.

Please contact MIUSA is you have access to relevant information, or if you would like to be notified when the booklet is available. Write to: DWD Project, c/o Mobility International USA, P.O. Box 10767, Eugene, OR 97440 USA.



Improving Your Rural Business with the ADA is a self-contained training resource package targeted toward rural business owners. It is a program that can be used to assist rural business owners as well as other community members in understanding and implementing the

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Americans with Disabilities Act (ADA). Business owners will learn how the ADA can have a positive impact on their businesses. Priority is given to providing information to help improve attitudes of business owners toward the ADA and people with disabilities.

The resource package (\$25.00) includes a 13-minute videotape about making rural businesses more accessible, copy-ready overhead transparencies, handouts and brochures as well as a leader's guide that will help in organizing and conducting an ADA training session. The videotape only is \$20.00. Contact: Breaking New Ground Resource Center, Purdue University, 1146 Agricultural Engineering Building, West Lafayette, IN 47907-1146 or 800/825-4264 (Voice/TDD).



Access America is the official publication of United States Architectural and Transportation Barriers Compliance Board, Suite 1000, 1331 F Street, NW, Washington, DC 20004-1111 (202/272-5434). Contact them for information about this newsletter and other pamphlets which include Detectable Warnings, Visual Alarms, Text Telephone, Parking, Using ADA Accessibility Guidelines, and Surfaces. Up to five copies of any of the pamphlets are available at no cost.



Several recently published Government reference books that provide guidelines for complying with the Americans with Disabilities Act (ADA) are available for sale from the Superintendent of Documents, U.S. Government Printing Office. To order these publications, indicate the appropriate stock number(s) and price(s) and send your check or money order to Superintendent of Documents, PO Box 371954, Pittsburgh, PA 15220-7954. You may also purchase by sending your VISA or MasterCard number and expiration date. Price includes shipping and handling.

American with Disabilities Act Handbook — Serves as the fundamental guide to all five titles of the ADA, including interpretive guidance for employment provisions (Title I), requirements for state and local government programs and services (Title II) and public accommodations and commercial facilities (Title III). (S/N 052-015-00074-0; \$34).

A Technical Assistance Manual on the Employment Provisions (Title I) of the Americans with Disabilities Act — Specifically covers the employment provisions of the ADA, such as hiring, compensation, fringe benefits, contractual arrangements and promotions. (S/N 952-020-00000-5; \$24 subscription).

The Americans with Disabilities Act Title II Technical Assistance Manual Covering State and Local Government Programs and Services — Describes ADA requirements and compliance responsibilities of state and local government programs and services. (S/N 927-008-00000-9; \$25 subscription).

The Americans with Disabilities Act Title III Technical Assistance Manual Covering Public Accommodations and Commercial Facilities — Discusses access issues in public places such as hotels, motels, retail and entertainment establishments, and business services. (S/N 927-009-00000-5; \$25 subscription).

Americans with Disabilities Act Guidelines Checklist — Provides step-by-step instructions, diagrams and requirement sheets to aid in the detection of access barriers and to ensure compliance with Titles II and III. (S/N 052-003-01323-1; \$20).

Americans with Disabilities Act of 1990, Public Law 101-336 — Official text of the Americans with Disabilities Act as issued by the 101st Congress. (S/N 869-010-00096-1; \$1.50)

The Arts and 504: A Handbook for Accessible Arts Programming, 1992 — Helps members of cultural organizations and persons with disabilities learn how programs and activities can be made more accessible and comply with Section 504 regulations. (S/N 036-000-00047-3; \$6.50).

Preservation Briefs 32 — Making Historic Properties Accessible — Focuses on how to make properties accessible while preserving historic qualities. (S/N 024-005-01121-8; \$1.50).



Our law firm is representing a number of women with silicone breast implants. From our contacts with physicians and from our review of the literature, we understand that some individuals who contracted polio were treated with silicone injections or with silicone implants. We also understand that some of these people are experiencing autoimmune and neurological problems, not unlike those seen in women with silicone breast implants.

We are interested in developing this evidence further since the manufacturers are defending these cases, at least in part, on the ground that silicone is biologically inert and not harmful.

If you or someone you know has had silicone injections or implants as treatment for polio, we would be interested in talking with you about that experience. Please contact me. Of course, all communications will be maintained in confidence. Thank you in advance for your help.

Leslie J. Bryan, Doffermyre Shields Canfield & Knowles, 1355 Peachtree St., Suite 1600, Atlanta, GA 30309 (404/881-8900).



Dirt and Disease: Polio before FDR by Naomi Rogers is a 258-page book published by Rutgers University Press, New Brunswick, NJ, 1992. It is available from your local bookstore in hardcover (ISBN O-1835-1785-00) and paper (ISBN 0-1835-1786-9).

Continued on page 11



Sixth International Post-Polio & Independent Living Conference

June 16th - 19th, 1994 • St. Louis Marriott Pavilion Hotel

AUDIO & VIDEO TAPES ORDER FORM

TAPE #1 G.I.N.I. Then & Now	Audio Cassette	VHS 1/2" Video
Post-Polio Syndrome 101: Acute Polio & Post-Polio Theories Date: 6-16-94 Time: 9:30—11:30 a.m.		
TAPE #2 Status of Polio in World Today Defining Post-Polio Problems Incidence & Prevalence of Post-Polio Date: 6-16-94 Time: 1:30—3:00 p.m.		
TAPE #3 Coordinating Post-Polio Treatment The Battle with Bracing Date: 6-16-94 Time: 3:30—5:00 p.m.		
TAPE #4 Post-Polio Corrective Surgery Recovery from Orthopedic Injury Date: 6-17-94 Time: 8:30—9:45 a.m.		
TAPE #5 Facing Surgery When Breathing is a Problem New Breathing Problems & New Swallowing Problems in Aging Polio Survivors Date: 6-17-94 Time: 10:15—11:30 a.m.		
TAPE #6 Finding Your Personal Threshold Determining Prescribed Activity Date: 6-17-94 Time: 1:30—3:00 p.m.		
TAPE #7 Choosing Correct Equipment Adapting to Using Adaptive Equipment Ideas for Relaxing Date: 6-17-94 Time: 3:30—5:00 p.m.		
TAPE #8 Disability As A Life Course — Theory & Research Separating Post-Polio Syndrome From Aging The Implications Date: 6-17-94 Time: 1:30—3:00 p.m.		
TAPE #9 From My Perspective Secondary Disability: My Family & Me Date: 6-17-94 Time: 3:30—5:00 p.m.		

TAPE #10 Improving Cough & Decreasing Infection Changing Equipment as Diagnosis Change Diaphragmatic Pacer Date: 6-17-94 Time: 1:30—3:00 p.m.	Audio Cassette	VHS 1/2" Video
TAPE #11 Living at Home: Overcoming Obstacles Date: 6-17-94 Time: 3:30—5:00 p.m.		
TAPE #12 Challenges Facing Individuals with Disabilities Date: 6-18-94 Time: 9:00—10:00 a.m. and 10:00—11:30 a.m.		
TAPE #13 Face Mask Show & Tell Date: 6-18-94 Time: 9:00—10:00 a.m. and 10:30—11:30 a.m.		
TAPE #14 Post-Polio Research: What's Being Done & What Needs to Be Done Date: 6-18-94 Time: 1:30—3:00 p.m.		
TAPE #15 Health Care Reform Date: 6-18-94 Time: 3:30—5:00 p.m.		
Information for Ordering Conference Tapes		
Please indicate which tape you would like by putting an X on the The cost of each audio tape (1-1/2 hours or less) is \$6 plus 5.725% 5.725% tax. Please add \$3.50 for postage and handling. Fill in the the tapes below.	% tax; each video casse	ette tape is \$12 plus
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We also accept American Express, Mastercard, & VISA

Potpourri Continued from page 8

Unfortunately, the American Public Welfare Association no longer has reprints of the two-part article "FDR; Handicapped American," as mentioned in *Polio Network News*, (Vol. 9, No. 4, Fall, 1993).



To receive a copy of the booklet *Treating Your Enlarged Prostate*, call 800/358-9295 or write to: AHCPR Publications Clearinghouse, PO Box 8547, Silver Spring, MD 20907.



The Very Special Traveler (ISSN 1072-8813) is a newsletter issued six times a year, edited by Beverly Nelson. To subscribe, send \$25 to: The Very Special Traveler, Box 166, 90 W. Montgomery Ave., Rockville, MD 20850.



Are you AT YOUR WITS END? is a bimonthly newsletter edited and published by polio survivors Michael and Barbara Morrione. For more information contact them at P.O. Box 1662, Southgate, CA 90280-8025.



ABLEDATA is a national database of information on assistive technology and rehabilitation equipment available from domestic and international sources. ABLE-DATA contains information on more than 18,000 assistive technology products. The database contains detailed descriptions of each product including price and company information. It also contains non-commercial prototypes, customized and one-of-a-kind products, and do-it-yourself designs. An information specialist can search ABLEDATA for different models of a specific device, such as powered wheelchairs, or for products which address a functional need, such as eating. A printed listing of fewer than 20 products is free; a fee of \$5.00 is charged per 100 products. Call 800/227-0216 or 301/588-9284 between 8:00 a.m. to 6:00 p.m. eastern time Monday through Friday except federal holidays, or write ABLEDATA, 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910.



Yes, We Saw *Time* Many have asked if we saw the March 28, 1994, *Time* article, "Reliving Polio." We did. The final article caused a range of responses, from "good and informative" to "misleading and incomplete." We would like to publish reactions to the article. Readers, both polio survivors and health professionals, are invited to send their thoughts and comments to IPN.



Conference Tapes To assist readers in ordering tapes, the final conference program for the Sixth International Post-Polio and Independent Living Conference will be available from our office on June 20, 1994. ■

Readers Request

- ♦ *Polio Network News* (Vol. 8, No. 2, Spring, 1992) published a note from Valerie Brew-Parrish regarding the removal of cancerous growths from her face which reminded her of a childhood experience. She remembers being taken to a room, as a student in a special school for children with disabilities, and exposed to ultraviolet light on a routine basis. Valerie wrote again recently, in view of the current revelation by the Department of Energy, to encourage those with disabilities recalling similar treatment to report this to the Department of Energy at 800/493-2998.
- ♦ Linda Bieniek, 2650 N. Lakeview, #607, Chicago, IL 60614, is interested in hearing from anyone who applied to the National Vaccine Injury Compensation Program making claim that their polio was caused by the Salk vaccine.
- ♦ *Polio Network News* has recently had several requests for information and solutions to low back pain due to severe scoliosis. Also, several survivors have requested information regarding shoulder/rotator cuff injuries and potential surgeries. Please send your experiences and suggestions to International Polio Network.
- ♦ "I wear different size shoes. Is there someone who would be interested in exchanging or buying women's shoes that consists of a left shoe size 4B and a right shoe size 6-1/2C?" Judy Keleshis, 16435 S. McRae Ave., Norwalk, CA 90650.
- ♦ "I take a 9 1/2 C on the left foot and 11 C on the right foot." Mark Eisenberg, 260-50 75th Ave., Glen Oaks, NY 11004.
- ♦ "I was born deaf, contracted polio, recovered, and am now experiencing the late effects of polio. I am interested in communicating with other hearing impaired polio survivors." Gail Geyer, 724 Chadwick Court, Pomona, CA 91766.
- ♦ "I would like to correspond with other post-polio individuals with scoliosis." Mrs. Helen Chingusky, 15 Van Winkle Dr., Rensselaer, NY 12144.
- "I'd like to hear from individuals who would write their polio experience as they know it, or as they were told of it. If you don't want to write it, I'd be willing to interview you in person or over the phone. I'd eventually like to see if a publisher would be interested." Cookie Anderson, 3053A S. Shore, Milwaukee, WI 53207.
- ♦ Kathryn Black is writing a book of her family's story and wants to recreate the culture of the country at the time of the epidemics. Specific memories, particular incidents, and memorable events, rather than a summary of the experience, are wanted from polio survivors and others who remember what it was like to live with the threat of polio. Send your thoughts to Kathryn Black, 861 11th Street, Boulder, CO 80302. ■

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

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Information Available from International Polio Network

- Handbook on the Late Effects of Poliomyelitis for **Physicians and Survivors**, a 48-page booklet in dictionary format, contains information about clinical problems associated with the late effects of polio based on the experiences of physicians and polio survivors. Edited by Gini Laurie, Frederick M. Maynard, M.D., D. Armin Fischer, M.D., and Judy Raymond. The cost of the booklet postpaid is \$6.75 in the USA and \$8 for all other countries. Bulk rates are available.
- **Post-Polio Directory 1994** contains four sections. The International section lists contacts in countries throughout the world interested in post-polio and disability issues. The entries for the U.S. are divided into three categories. Physicians and facilities providing specialized and comprehensive treatment for polio survivors are listed under Clinics. Many individual health professionals have expertise in treating polio survivors and are listed along with their areas of medical specialties under Health Professionals. The Support Group section lists support groups, along with a contact person. Some names listed are resource only and are designated as such. The Directory is for information purposes only. A listing does not imply endorsement by the International Polio Network.

The cost of the Directory is \$3 for polio survivors; \$6 for others; Canada, Mexico and overseas add \$1; Overseas airmail add \$2.

■ Back issues of **Polio Network News** are available for \$3 each. Below is a list of featured topics and the volume and number of Polio Network News in which they appear. A yearly subscription to Polio Network News is \$12 for survivors; \$20 for others; Canada, Mexico, and overseas add \$4; overseas air add \$8.

Underventilation: A Warning (Vol. 4, No. 2) Let's Talk About Oxygen and Polio (Vol. 6, No. 3) The Diagnosis of Underventilation Following Polio, and Treatment of Underventilation by Day and by Night (Vol. 6, No. 3) Foot Problems Due to Polio (Vol. 4, No. 2) People Keep Coming: The Brief Story of a Support Group

(Vol. 7, No. 4) Vocational Rehabilitation: Still a Valuable Resource

Solutions to Foot Problems Due to Polio (Vol. 4, No. 3) Braces Do Not Mean Ugly Shoes (Vol. 8, No. 1) Support Groups (Vol. 4, No. 4) Thoughts on Self-Help (Vol. 7, No. 1)

A Post-Polio "Normal's" Reconciliation with the Ghost of Polio Past, Part I (Vol. 5, No. 4), Part II (Vol. 6, No. 1) Hydrotherapy Program for Patients with the Post-Polio Syndrome (Vol. 6, No. 1)

A Case for Re-evaluating Physical Therapy as a Viable Extended Treatment of Polio Individuals in the 1990s, Part I (Vol. 7, No. 3), Part II (Vol. 7, No. 4)

Becoming an Intelligent Consumer of Physical Therapy Services, Part I (Vol. 9, No. 1) Part II (Vol. 9, No. 2)

Prescription for Fatigue (Vol. 6, No. 2)

for Polio Survivors (Vol. 5, No. 1)

Prescription for Weakness (Vol. 6, No. 3, Vol. 7, No. 1)

Prescription for Pain (Vol. 6, No. 4)

A Review of Swallowing Difficulties in Post-Polio Indiv iduals (Vol. 6, No. 4)

A Look at Carpal Tunnel Syndrome (Vol. 7, No. 2)

A Ten Year Experience (Vol. 7, No. 2)

Suggestions for Exercise (Vol. 7, No. 3)

Scoliosis (Vol. 8, No. 2, Vol. 8, No. 4) US Post-Polio Clinic Survey Results (Vol. 8, No. 3)

Exploring Your Options (re: surgery) (Vol. 8, No. 2)

What's Happening with Research Medications (Vol. 8, No. 4)

Osteoporosis (Vol. 9, No. 3)

Nutrition Odds and Ends (Vol. 9, No. 4)

- Five copies or less of the pamphlet, *The Late Effects of* **Polio** — **An Overview**, are available free of charge. Other quantities are available as follows: 6-25 copies \$3; 26-50 copies \$6; 51-75 copies \$9; 75-100 copies \$12. Also available
- A packet of information for starting a post-polio support group, including Post-Polio Support Group Philosophy, Guidelines, and Resources, is available for \$5.
- *I.V.U.N. News* is a biannual newsletter edited by Judith Raymond Fischer providing information and networking for ventilator users, their families, and health professionals committed to home mechanical ventilation. A yearly subscription to I.V.U.N. News is \$8 for ventilator users; \$20 for others; Canada, Mexico, and overseas add \$2; overseas air add \$4.

To order send request and check payable to G.I.N.I., 5100 Oakland Ave., #206, St. Louis, MO 63110-1406 USA.