

## ◀ RADIO

Robert Enteen, PhD, creator and host of "Health Update with Dr. Bob Enteen," has started a new independently produced program entitled "Disability and Health Today." The first show was aired January 3, 1995 via the public radio satellite system. To find out if the show is aired in your area, contact your local National Public Radio station.

## ▶ VIDEO

**People in Motion: An Innovation Miniseries** looking at living with a physical disability, challenges to stereotypes, latest technology, and changing attitudes debuts March 31, 1995 on PBS. Violinist Itzak Perlman hosts the Miniseries produced by Thirteen/WNET in New York. *People in Motion* will air three consecutive Fridays — March 31, *Ways to Move*; April 7, *Ready to Live* (includes Ed Roberts, a polio survivor now at World Institute on Disability); April 14, *Redesigning the Human Machine* — at 9:00 p.m. (ET) on PBS. Check your local listings.

**Epilepsy: The Untold Story** is a new video from Fanlight Productions which explores life with Temporal Lobe Epilepsy. Contact Fanlight Productions, 47 Halifax St., Boston, MA 02130 (800/837-4113) for purchase or rental information.

## ◀ READING

**Social and Psychological Foundations of Rehabilitation** by Robert A. Chubon, PhD, with foreword by Frank G. Bowe; Charles C Thomas, Publisher; ISBN 0-398-05920-9 (hbk).

**Chronic Disease and Disability: A Contemporary Rehabilitation Approach to Medical Practice** by Ross M. Hays, MD, George H. Kraft, MD, and Walter C. Stolov, MD; Demos Publications, 386 Park Ave., S., New York, NY 10016; ISBN 0-939957-46-9 (pbk); \$29.95.

**Post-Polio Syndrome** edited by Lauro S. Halstead, MD and Gunnar Grimby, MD, PhD; Hanley and Belfus, Inc. Medical Publishers, 210 S. 13th St., Philadelphia, PA 19107 (800/962-1892); (hard cover, 300 pages) \$32.95 USA, \$37.95 outside USA.

**Healing The Blues: Drug-Free Psychotherapy for Depression** by Dorothea Nudelman, patient (polio survivor), and David Willingham, MSW, therapist; The Boxwood Press, 183 Ocean View Blvd., Pacific Grove, CA 93950 (408/375-9110); ISBN 0-940168-31-6; \$22.00 plus \$2.25 S&H.

**We Overcame, The Story of Civil Rights for Disabled People** by Richard Bryant Treanor; ISBN 0-9631345-2-3 (pbk); \$14.95 plus \$2.05 S&H; We Overcame c/o Richard B. Treanor, 613 4th Pl., SW, Washington, DC 20024.

**Issues in Rural Independence**, a series of six (attitudes, accessibility, funding, housing, transportation, demonstration sites) monographs; \$6.50 each or \$30 for series; ILRU, 2323 S. Shepherd St., Suite 1000, Houston, TX 77019 (713/520-0232 V, 520-5136 TTY).

**Guidelines for the Use of Assisted Technology: Evaluation, Referral, Prescription;** Dept. of Geriatrics Health, American Medical Association, 515 N. State St., Chicago, IL 60610 (312/464-5085); ISBN 0-899-70-694-0; Single copies \$5, package of 25 \$100. These guidelines were developed for primary care physicians to help them efficiently and effectively meet the needs of their patients with disabilities.

**Living with Osteogenesis Imperfecta, A Guidebook for Families**, edited by Heidi Glauser; \$19.95 plus \$2.55 handling from Osteogenesis Imperfecta Foundation, Inc., 5005 West Laurel St., Suite 210, Tampa, FL 33607.

**Guide to Toys for Children Who Are Blind or Visually Impaired;** free from American Foundation for the Blind, 800/232-5463 or Toy

Manufacturers of America FAX  
212/633-1429

The newly-revised **The Disabled Driver's Mobility Guide** is now available for \$5.95 from your local AAA, or by contacting the national office, 1000 AAA Dr., Heathrow, FL 32746-5063 (407/444-7000).

**Assessing Children for the Presence of a Disability in News Digest** (Vol. 4, No. 1, 1994) is available free from NICHCY by calling 800/695-0285.

**In the Mainstream** (Vol. 19, No. 6, 1994) contained **To Tell or Not to Tell: Disability Disclosure and the Job Interview**. Contact Fritz Rumpel, Editor, Mainstream, Inc., 3 Bethesda Metro Center, Suite 830, Bethesda, MD 20814 (301/654-2400).

For the new version of the "**Blue Book**," Disability Evaluation Under Social Security (SSA Pub. No. 64-039) and a new pamphlet, **A Guide to Pulmonary Function Studies under the Social Disability Program** (SSA Pub. No. 64-055), contact SSA, DDPP, PRB, Room 3-A-10 Operations Building, 6401 Security Blvd., Baltimore, MD 21235. ■

**EMI** Laboratory tests performed by the Food and Drug Administration (FDA) have shown that radio waves can cause unintended motion of powered wheelchairs and motorized scooters. Radio waves are a form of electromagnetic energy and when this energy unintentionally affects the operation of a device, it is called "electromagnetic interference" (EMI).

Radio waves are emitted from the antennas of cellular phones, mobile two-way radios (like those used in police, fire and emergency vehicles), hand-held two-way radios (like walkie-talkies), radio stations, TV stations, amateur radio (HAM) transmitters, wireless computer links, microwave sources, and paging transmitters.

The kind of motion to expect depends on a number of factors, including: the intensity of the radio waves, the construction of the powered wheelchair or motorized scooter, whether it is on level ground or on a slope, and whether it is in motion or still. The motion can be erratic, with the powered wheelchair or motorized scooter moving by itself or coming to a sudden stop. It is possible for EMI to unexpectedly release the brakes on a powered wheelchair or cause it to go in unintended directions. Some intense sources of EMI can even damage the control system of the powered wheelchair or motorized scooter.

Each make and model of powered wheelchairs and motorized scooters differs in its ability to resist EMI. Each has a particular level of "immunity" to interference, measured in volts per meter (V/m). The higher the immunity level, the greater the protection.

The FDA has written to the manufacturers asking them to test their new products to be sure they provide a reasonable degree of immunity against EMI. Powered wheelchairs

and motorized scooters should have an immunity level of at least 20 V/m. (Contact the manufacturer to find out the immunity level of any equipment you now own.)

FDA is asking manufacturers to label new products with the immunity level (or else state that the immunity level is not known). The labeling and information material must explain what the immunity level means, and warn users about the possibility of EMI and how to avoid it.

If you've had your powered wheelchair or motorized scooter for a long time and haven't experienced any unintended motion, it's not likely that you'll have problems in the future. But it's always possible that problems could arise if you're close to a source of radio waves. So it's important to be alert to this possibility.

*If unintended motion or brake release occurs, turn the powered wheelchair or motorized scooter OFF as soon as it is safe.*

*You should report the incident to the manufacturer and/or distributor and FDA's MedWatch problem reporting program. Call 1-800-FDA-1088 and ask for Form 3500. ■*

SOURCE: Department of Health & Human Services, Office of Health and Industry Programs, Center for Devices and Radiological Health, Food and Drug Administration, Rockville, MD.

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To receive **Safety in the Bathroom: Products to Assist with Bathing — Benches and Lifts** (\$3.00) or **Bath Seats** (\$3.00) contact CAT/UB Products, Center for Assistive Technology, 515 Kimball Tower, University at Buffalo, Buffalo, NY 14214-3079. (Checks to UB Foundation, Inc.). Both booklets are available for \$5.00. A small catalog lists their other products.

## **Here are some precautions you can take:**

- 1** Do not turn ON or use hand-held personal communication devices, such as citizens band (CB) radios and cellular phones, while the powered wheelchair or motorized scooter is ON.
- 2** Be aware of nearby transmitters, such as radio or TV stations and hand-held or mobile two-way radios, and try to avoid coming close to them. For example, a powered wheelchair or motorized scooter with an immunity level of 20 V/m should stay at least three feet from a hand-held two-way radio and ten feet from a mobile two-way radio.
- 3** Be aware that adding accessories or components, or modifying the powered wheelchair or motorized scooter, may make it more susceptible to interference from radio wave sources.

# Break It Up!

The Nutrition and Labeling Act of 1990 established new standards for food labels. Breaking the label into three parts makes it easier to follow:

Nutrition Facts	
Serving Size: 1 oz. (1 bar)	
Amount Per serving	
Calories 130	Calories from Fat 60
	% Daily Value*
Total Fat 7g	11%
Saturated Fat 4g	20%
Cholesterol 0mg	0%
Sodium 55mg	2%
Total Carbohydrate 18g	6%
Dietary Fiber 1g	4%
Sugars 13g	4%
Protein 4g	4%
Vitamin A 0%	Vitamin C 0%
Calcium 4%	Iron 4%
*Percent Daily values are based on a 2,000 calorie diet. Your daily value may be higher or lower depending on your calorie need:	
	Calories: 2,000 2,500
Total Fat	Less than 85g 80g
Sat Fat	Less than 20g 25g
Cholesterol	Less than 300mg 300mg
Sodium	Less than 2,400mg 2,400mg
Total Carbohydrate	Less than 300g 300g
Dietary Fiber	Less than 25g 30g
Calories per gram: Fat 9 • Carbohydrate 4 • Protein 4	

**THE TOP SECTION** highlights excess nutrients. Some people consume too much of these.

**THE MIDDLE SECTION** lists a few key nutrients that help keep you healthy. They're also the ones in which you're most likely to be deficient.

**THE "FOOTNOTE"** tells you that the nutritional information is based on a 2,000-calorie daily diet. If you eat more or less than 2,000 calories a day, adjust the percentages.

# For Your Health

**The Percent Daily Values** can help you compare similar foods to see which is the most "nutrient dense." Nutrient-dense foods contain between 10% and 19% of the key ingredients found on the middle of the nutrition fact label: Vitamins A and C, calcium, iron, protein, and fiber.

The Dairy Council has created an easy way to compare foods by using the number 10 and your fingers. Look at the middle portion of the Nutrition Facts label.

Start with a closed fist. Raise a finger if the food has: 10% or more Vitamin A; 10% or more Vitamin C; 10% or more Calcium; 10% or more Iron; 10% (5g) or more protein; 10% or more fiber.



Lower a finger if the food has either: 10% or more total fat or 200 calories or more. If any fingers remain up, the food is nutritious. ■

## Get involved!

☐ "Thanks for sending me the wonderful material which inspired us to publish our own polio survivors' manual in the Thai language. Our Foundation has been conducting medical evaluation clinics at the Yad Fon Vocational Training Center for the Disabled. What we have found is that of the current 26 students, 25 of them have never seen a doctor in regard to their polio. The reality is that 25 of these young adults have never received corrective surgery (where applicable), they have never been fitted for, or worn braces, and they have never received any kind of rehabilitation much less information about their disability.

"Dr. Sangroj Pradupkaew, MD, the director of the McKean Rehabilitation Center, has volunteered his time, but we still must confront hospital costs, rehab costs, and brace and wheelchair expenses.

"I am looking for sponsors, sources of funds, donations, foundations, newsletters, or any information which may assist us in helping these young adults." Donald J. Willcox, Director, Foundation for Support and Development of Disabled Persons, Chiang Mai Office, 195/197 Ban Tanawan, Moo 8, Tambon, Sanpheeseu, Amphur Muang Chiang Mai 50300, Thailand. Phone and FAX 66-53 240935.

☐ The National Council on Disability (NCD) has congressional authority and responsibility to monitor ADA's implementation. As they prepare for the fifth anniversary of ADA, NCD would like to receive your personal stories as to the law's impact on your life, particularly about successes and methods you have used to achieve success. Stories can be about your personal experiences, those of your employer, or changes in your community. National Council on Disability, 1331 F Street NW, Suite 1050, Washington, DC 20004-1107.

☐ Several leaders of the disability rights movement have formed Disabled and Able to Vote to send the message to politicians that it doesn't matter what party they belong to, they "can't afford to ignore 49 million people with disabilities, their families, and friends." For more information contact: Fred Fay, 2054 Main St., Concord, MA 01742 (508/371-0992); Becky Ogle, Project AccessAbility, 625 Slaters Lane, Suite 200, Alexandria, VA 22314 (703/836-6263); Allen Gray, 6149 Edsall Rd., Unit E, Alexandria, VA 22304 (703/823-8166, 202/484-1370 TDD).

• On the day the new 104th U.S. Congress assumed office almost one-half of the House of Representatives will have served two years or less. This means they were not in Congress during the discussions surrounding the Americans With Disability Act (ADA).

Congress is considering measures to curb future unfunded mandates. Note that the already passed Americans With Disabilities Act is many times listed as a "federal unfunded mandate." In a recent letter to disability advocates, Justin Dart comments, "ADA is not an unfunded mandate. It is a civil rights law that simply extends to Americans with disabilities the same constitutional protection that other Americans already enjoy."

• The German disability rights movement succeeded in getting an anti-discrimination clause included in the new constitution. In Article 3 it states, "No one shall be discriminated against because of disability."

• World AIDS day, December 1, 1994, focused on AIDS and the family, highlighting the crucial role of families in responding to the human immunodeficiency virus and acquired immunodeficiency syndrome (AIDS) pandemic. An estimated 17 million persons worldwide have been infected with HIV since onset of the pandemic and each day 6,000 additional persons become infected. The World Health Organization estimates that by the year 2,000 approximately 10 million children will have been orphaned because their parents died as a result of HIV infection. For more information contact the CDC National AIDS hotline (800/342-2437; Spanish, 800/344-7432; TTY/TDD, 800/243-7889). ■



**Long-time G.I.N.I. Board Member Penny Chrisler, and her husband Tanner,** recently celebrated their 40th wedding anniversary. Tribute gifts were received from Adrienne J. Shuter, Gayla and Arthur Hoffman, Jerry and Rosalie Grsch, Art Madsen, Dick Deverell, Joe Leone, and Joan Headley. Congratulations to both of you and thanks for your years of support.



**Tributes** were also received in memory of St. Louis G.I.N.I. friends *Pidge Cole* and *Priscilla Russell*. Both ladies had such presence. Our local support group truly misses them.

With regret we have learned that *James Donald*, Winnipeg, Manitoba, passed away. Jim attended G.I.N.I.'s recent conference.

• *Irving Kenneth Zola*, Professor, Brandeis University, Waltham, MA, died of a heart attack December 1, 1994. His personal and professional work on behalf of people with disabilities established him as a pioneer in disability studies where he was highly respected.

In the book, *Independent Living for Physically Disabled People* (1983), which he co-authored with Nancy M. Crewe, Irv made the following comment about his many years of struggling to walk, as a survivor of polio, many times all alone, taking five times as long, and arriving exhausted, thinking that he was physically independent. "The point is clear: In living in accord with someone else's definition of physical independence I, for far too long, contributed to the demise of my own social and psychological independence."

• G.I.N.I. was remembered in the last will and testament of long-time friend *Robert E. Hitz*, Lakewood, Ohio, who died in February, 1994. *Gazette* readers will remember that Robert was diagnosed with Marie-Strumpell arthritis, which caused the joints in the spine and hips to grow solid. Robert chose to live the rest of his life in a standing position, and was house confined because, as he said in a 1988 *Gazette* article, "chairs and stairs begin as soon as I leave home." He sought advice and continued "obviously, the place to start is where you are, but it was a lonely feeling to have people who claim to know about rehab come up dry. The *Rehabilitation Gazette* found me and revealed a whole new view of disability and rehabilitation to me. I was no longer alone." Robert Hitz went on to run a very successful insurance agency from his home.

• *Thomas Wallace Rogers*, Moline, IL, died in late August, 1994. Tom had polio in 1953 at age 19 and became a successful businessman, financial planner, and investment advisor. Tom was a trustee of several groups, including The First Congregational Church, Moline. He also held several Board directorships including the G.I.N.I. Advisory Board.

In the 30th anniversary issue of *Rehabilitation Gazette*, Tom described himself as a "breathing impaired quadriplegic" who "developed a great proficiency in frog breathing." Describing his parents, he wrote, they "provided a rich, fun, merry, fascinating life at a sacrifice to their own life styles, but they never let me feel that I thwarted them at any time."

He always gave credit to his brothers, secretaries, personal assistants, nurses, physicians, and his long-time friend and wife, Kera. Tom, through his family and Oscar A. Schwartz, MD, designated funds and donations to The Thomas Wallace Rogers Memorial Respiratory Research Fund to be established by G.I.N.I. Many of Tom's friends have honored his memory in this way. Tributes may be sent to G.I.N.I. making checks payable to The Thomas Wallace Rogers Memorial Respiratory Research Fund.



### REHABILITATION GAZETTE

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#### G.I.N.I.

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EDITOR: Joan L. Headley

**Jacquelin Perry, MD**, Rancho Los Amigos Medical Center, Downey, California, was named Physician of the Year by the California Governor's Committee for Employment of Disabled Persons. Dr. Perry continues to run the polio clinic and laboratory program at Rancho, which is good news for polio survivors in Southern California and everywhere. • *Tri-State Polio Support Group* honored polio survivor **Jessie Easton, MD**, who retired as Chief of Physical Medicine and Rehabilitation at the VA Hospital in Sioux Falls, South Dakota. She will keep her office hours and private practice, work with the post-polio clinic at McKennan Hospital in Sioux Falls, and will travel across the state as a consultant for children with disabilities. Retiring? • Polio survivor **Carl Larson**, Seattle, Washington, after seven and one half years of editing their polio newsletter, has decided to turn his energy to D.A.H.R.T. (Disabled Americans Have Rights Too), however, he will occasionally contribute to his former newsletter. Good job, Carl, and stay in touch as you help tackle the bigger picture. • **Ála Wokoun**, Czech Republic, reports that the Czech and Slovak Polio Associations will provide a program this summer at a Slovak recreation center. Czech survivors also plan a visit to a spa in Wiesbaden, Germany.

**Lori Hinderer** experienced a stroke last October. The stroke affected Lori's right side — the hand used to operate her electric wheelchair — and her swallowing and speech. Her swallowing and speech are improving, and she is working on ways to do things left-handed. Lori was a panelist at the most recent G.I.N.I. conference and contributed an article for *I.V.U.N. News* in 1992 "Travel by Air 'with Air' is Possible" (Vol. 6, No. 1) which featured her experiences and advice on traveling with an Aequitron LP-6 which she uses 24 hours a day because of muscular dystrophy.

**Adolf Ratzka, PhD, and Doro**, have a new address: Petersens Vag 2, 127 41 Stockholm-Skarholmen, Sweden. In his recent letter to G.I.N.I., Adolf writes "I have been reducing my workload except for my involvement in Stockholm Cooperative for Independent Living (STIL). Through my work at STIL a new bill was introduced in parliament last year. The reform provides direct payment from the national social insurance fund to users of personal assistants. Need is assessed on the basis of a person's whole social situation not on medical grounds. Payment per hour to personal assistants covers union wages, all the employer's contributions to social security, and the employer's administration costs. Expenditures such as my assistant's

travel costs are also covered. This bill has enabled many people to hire their own personal assistants.

"I was appointed to the council of the Office of the Ombudsman on Disability, which will work for new civil rights legislation. Talking about civil rights, Doro and I have been fighting the Swedish authorities for our right to adopt a child. I am considered unfit to be a father by the local government which, according to Swedish law, has the monopoly in conducting the home study and to decide whether a couple or single person may adopt. There is a politically appointed committee of lay persons who make the decisions on the basis of suggestions by a staff of social workers. We have been continually turned down by them solely on the basis of my disability and have appealed their decisions, winning five times in the higher court that the disability is not a hindrance (this committee re-appealed each time they lost). We finally did win in the highest Swedish court last summer.

"We are currently in San Jose, Costa Rica, because I was appointed as Visiting Professor in Disability Studies at the University of Costa Rica. We also have high hopes of adopting a baby girl whom we found here. We can be reached in Costa Rica c/o Dr. Federico Montero, P.O. Box 845-1007, San Jose."

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*Enclosed is my generous contribution to support G.I.N.I. in its work.*

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G.I.N.I.'s Federal ID No. is 34-0961952

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 5100 Oakland Ave., #206  
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**B**orn in St. Louis, Missouri, in 1938, I had polio in June, 1946, after having chicken pox and measles earlier. I was diagnosed at DePaul Hospital and moved to City Hospital where I spent one week in an iron lung. After another two and one half months of rehab at Lutheran Hospital, I had no muscle return in my legs. In October I went home fitted with a back and leg braces, using a wooden wheelchair.

My parents sought additional treatment for me at County Hospital on an outpatient basis until full-time treatment was available. (That polio clinic was later moved to St. Anthony's Hospital.) At St. Anthony's, I roomed with Shirley Kopecky who was on a stretcher during the day and relied on an iron lung at night. It was not unusual for us to be seen together, me and my metal, collapsible chair paid for by the March of Dimes, pushing her on the stretcher.

In 1949 when another epidemic hit I was sent home but continued outpatient treatments and, in 1953, we moved to the City of Dellwood, in North County St. Louis. At Riverview Gardens high school I was able to attend with the rest of the students because the principal arranged all my classes on the same floor. I was just a regular student serving on the year-book staff, a member of the pep club, and National Honor Society.

As graduation neared, my counselor encouraged me to go to college with tuition assistance from vocational rehabilitation. The building where I had 75% of my classes had an elevator and the restrooms were large enough. The rest of the time fellow students assisted me up and down the steps.

In 1961, I received my BSC with a degree in accounting from St. Louis University School of Commerce and Finance, which corresponds with the time I stopped wearing the leg braces. It was not a simple task for a female to get a job in the accounting field, so I explored starting a small office in my home. But, by January of 1965, I was hired by my church as financial secretary.

In the next few years I developed abdominal discomfort associated with my menstrual cycle. My doctor prescribed birth control pills and within a short time a blood clot formed in my left groin. It required several weeks hospitalization to treat but the underlying problem of pain remained. The doctor recommended I not use my back support at least temporarily. I stopped wearing it and did not wear it again (at least for 20 years). Ultimately, I was diagnosed with endometriosis. For four years, we tried a number of drugs because he was very cool to my suggestion of a hysterectomy. After getting a second opinion, he performed the surgery in 1971. After recovery and getting my body back in shape, life took an upward turn.

*"I have learned to do a better job of listening to my body."*

In 1971 I received a telephone call from a Gini Laurie who was back in St. Louis with her husband. She had connected with Shirley Kopecky, my old hospital roommate, who told her I did accounting. And so my relationship with Gini and Joe Laurie had its beginning.

They would pick me up and drive me to their home on Maryland Avenue where I did their accounting. Gini exposed me to a whole new world and introduced me to other individuals with disabilities. One couple, both of whom were disabled, had a van with a wheelchair lift and hand controls. The following year we had a porch lift installed enabling me to get in and out of the house by myself. Another step closer to independence.

When I was 36, Gini asked if I had ever talked to my DVR counselor about the possibility of getting a van with equipment for myself. I had long dreamed of driving so I did. They would not purchase a van, but they would financially help with the adaptable equipment, and, in January 1974, the deed was done. Thanks to

a very loving and caring neighbor, Paul Finkes, who taught me how to drive my new 1974 Chevy with a side, sliding door, I got my driver's license in April. Since transferring took too long and wore me out, and because I never felt secure without the arm rests the wheelchair provided, I drove locked down in my chair. The hand controls, which I used to accelerate and stop, were mounted on the right side of the steering column. I steered with my stronger left arm.

The added independence allowed me to take a job in sales with a company in St. Charles, Missouri, that installed equipment for the disabled. Economic circumstances forced their closing in 1980 and I worked for three months at a medical supply company. Also I continued my duties as financial secretary at church, as well as the book work for G.I.N.I. This finally took its toll.

My stamina was depleted. I felt like I constantly had the flu and was TIRED all the time. I was hospitalized for tests and nothing specific was found. I became intolerant of some foods and now completely avoid wheat, pork, eggs, and chocolate. I also noticed more allergy symptoms and began weekly allergy shots which I continue to receive administered by my mother with whom I live.

I still did not have the energy I once had enjoyed, and, in the spring of 1981, I applied for disability benefits and received them without a problem. What work I did at home was not considered substantial.

In the early '80s, Gini Laurie asked me if I would be interested in attending a post-polio support group. I really felt I didn't need that kind of help, but agreed to come just for Gini. At our first meeting Oscar Schwartz, MD, a pulmonologist, came to speak to us. I remember some 25-30 people surrounding him in a not-so-big room. He spoke briefly on problems some people were having and just answered our questions for over an hour. I seldom have missed a support group meeting since.

By the mid-80s, my left shoulder ached much of the time. So I decided

to see what this new Dr. Schwartz was like. He was very thorough in his evaluation and prescribed respiratory therapy using a forced cough bag to help maintain my lung capacity. He sent me to physical therapy and recommended not pushing my wheelchair as much as possible, so I could rest the shoulder joint. We tried heat packs but ice packs and anti-inflammatories solved the problem. My therapist, Betty Marshall, RPT, recommended I change my wheelchair cushion from a three-inch upholstery-type foam rubber to a Roho cushion because it is a "more forgiving" cushion.

While getting the new cushion, I spied some literature on an add-on power pack for wheelchairs. I showed it to Betty who was not sure Medicare would pay, but suggested Dr. Schwartz write a medical necessity for it and perhaps it would be accepted. It was. Now I had power.

Dr. Schwartz's specialty was respiratory and, in 1987, Martin Wice, MD, a physiatrist from St. John's Mercy Medical Center, was interested in starting a polio clinic. Gini Laurie was impressed with the team of professionals at St. John's and any worries about upsetting the relationship with Dr. Schwartz were unfounded. Both physicians were willing, and continue, to work together referring patients to each other.

Because I had attended G.I.N.I. conferences, I became more interested in how I could better care for myself. I bought an Apple II GS and set about learning how to use it by myself. The computer allows me to do my accounting tasks which used to take days, in hours, with less fatigue. In 1993, I acquired an IBM-compatible to further expand my abilities.

I mulled this new Dr. Wice over in my mind and finally, in 1987, felt it would be a good idea to have an evaluation to establish a baseline of paralysis and curvature of the spine. After he had given me a thorough evaluation, I asked about support for my back. He was pleased I had already been evaluated by Dr. Schwartz for my pulmonary needs but was hesitant about the back support because of

my limited pulmonary capacity. He suggested range of motion exercises for my arms and a rest period every afternoon for about an hour or so to give my neck and shoulders a rest. I do so almost every day. I continue to see both doctors regularly each year.

In the spring of '88 I had my first disability review, and it was at that point I realized how valuable medical documentation is. Having been evaluated by both doctors, the SSA was able to easily access the necessary information.

In the early '90s, I began having neck and shoulder tightness and more weakness in those areas. Even driving had become a challenge partly



because of my physical decline and partly because of my van's mechanical decline. Driving now required someone with me wherever I went, and I found myself just staying home.

Dr. Wice ran tests to see if anything else had changed. It was evident that I was wearing out my neck and shoulder muscles just holding myself up during the day. I again asked about a back support, and this time we decided to give it a try watching for any respiratory problems.

I have to say that the addition of the back support, which holds me more erect, was a major turnaround for me. It is made of plastic with fasteners of cloth strips and velcro. Dressing has become more difficult since I don't have as much flexibility. I do feel I have gained back a little strength in my neck and shoulders. I also have found the use of a soft cervical collar helpful.

In addition, I visited a psychologist who determined I was not experiencing depression but assisted me in learning relaxation techniques such as deep breathing.

Dr. Wice prescribed a full power wheelchair, and in the fall of 1991, I got an Invacare Power 9000. They had to adjust the seat and modify the joy stick so it could pivot out of the way when at tables and driving. The new arm rests were shorter which required some adjusting to, and I still use a Roho. However, I can no longer "be assisted" up small steps because of the permanent anti-tip devices.

With the new chair I also purchased a Chevy van which has anti-lock brakes and is much better insulated. The conversion was done by United Medical Mart, St. Louis. It has a side door lift, same configuration but new hand controls, and the wheelchair locking mechanism is powered — when I roll in place it automatically locks me in. I also replaced my old CB with a cellular phone. I have adjusted to my new chair and van and still do the books for my church and G.I.N.I., driving myself to them.

I have learned to do a better job of listening to my body. If I know I am going to have a long day then I must allow more time the next day to recover, and if possible to rest a little more the day before.

I do not know how much longer I can continue to depend on my dear mother. We take care of each other. Hopefully, I will be able to obtain personal assistance at least on a part-time basis. However, this will depend on whether or not funds are available.

In retrospect, I feel there are four very important groups in my life. The first, of course, is my family, the second is my church family, the third is my neighbors, my friends across town and my G.I.N.I. friends across the country, and the fourth is the medical community that meets my needs. That doesn't leave much left, does it? But you never know when or where a helping hand may come from, and, hopefully, learn from as well. ■

Gazette International Networking Institute's  
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Also Publisher of

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**1995 MARCH** Fifth International Conference on Pulmonary Rehabilitation and Home Ventilation, March 12-15, Hyatt Regency Hotel, Denver CO. Program Chairman: Barry Make, MD. Contact National Jewish Center for Immunology & Respiratory Medicine, Office of Professional Education, 1400 Jackson St., Room M/222, Denver CO 80206. 303/398-1359. **APRIL Ventilator Assisted Children's Center (VACC) Camp**, Miami, April 1-7. Contact Cathy Klein, VACC Coordinator, Miami Children's Hospital, 3200 S.W. 60th Court, Suite 203, Miami FL 33155-4076. 305/662-VACC. **Polio Update Conference**, April 1-2, Pooks Hill Marriott Hotel, Bethesda, MD. Contact Jessica Scheer, PhD, Polio Society, 4200 Wisconsin Ave., NW, Suite 106273, Washington, DC 20016 (301/897-8180). **Post-Polio Conference**, April 8, Best Western Motel, Anderson, IN. Contact Ellen Crim, 338 West 38th St., Anderson, IN 46013 (317/649-3648). **MAY NCIL 13th Annual Conference**, May 12-16, Bethesda Hyatt Regency, Bethesda, MD. Contact Ed Graves, NCIL, 2111 Wilson Blvd., Suite 405, Arlington, VA 22201. **President's Committee on Employ-**

*Things to Do*

**ment of People with Disabilities Annual Conference**, Portland, OR, May 17-19. Contact: Betsy Friedman at President's Committee by FAX 202/376-6219. **Polio: Past, Present, Future**, Birmingham, AL, May 19-20. Contact: Ellen Peak, 625 26th Ave., N.W., Birmingham, AL 35215. **JUNE AT Expo '95, Adaptive Technology Expo of the Rockies**, June 2-3, Colorado Convention Center, Denver, CO. Contact Jan Cohen (800/332-9733). **Paradigms of Care**, 76th Annual Meeting, American Congress of Rehabilitation Medicine, June 22-25, Hyatt Regency Crystal City, Arlington, VA. Contact: Kathy Billa, 708/966-0095 Ext. 2204 **AUGUST International Symposium on Women with Disabilities**, August 29, immediately precedes UN World Conference on Women's NGO (non-governmental organization) Forum, August 29-September 8, 1995, Beijing, China. Contact NGO foreign secretariat, attention: Ann Berancon, 211 E. 43rd St., Suite 1500, New York, NY 10017 (FAX 212/

922-9269). **SEPTEMBER European Respiratory Society**, Annual Congress, September 16-20, Barcelona, Spain. Contact European Respiratory Society, 60 rue de Vaugirard, F-75006 Paris, France. **Provincial Post-Polio Conference**, bilingual, September 23-24, Montreal, Quebec. Contact Sally Aitken, Polio Quebec Association, C.P. 745, Succursale Jean-Talon, Montreal, Quebec, H1S 2Z5 (418/935-9158). **OCTOBER International Symposium and Exhibition on Orthopedic and Paralysis Sequelae Rehabilitation**, Beijing, China, October 16-20. Contact: Mr. Hejian, China International Conference Center for Science and Technology (CICCST), 44, Kexue Yuan Nan Rd., Shuang Yu Shu, Hai Dian, Beijing 100086, P.R. China. **1995 Abilities Expo**, March 10-12, Florida State Fair Expo Park, Tampa, FL; April 21-23, Anaheim Convention Center, Anaheim, CA; June 16-18, Raritan Center Expo Hall, Edison, NJ; August 11-13, Rosemont Convention Center, Chicago Area; September 29-October 1, San Mateo Expo Center, San Francisco Bay Area. For more information call 203/256-4700. ■

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