

POLIO NETWORK NEWS

FALL 1993 ♦ VOL. 9, NO. 4

International Polio Network

Gini and G.I.N.I. Conferences

Pioneering Independent Living

By Gertrud Weiss
Rosenheim, Germany

Erika Bulow, a polio survivor and friend in Berlin, was shocked and, at the same time, relieved when she learned from some of my articles three years ago, that her mysterious new health problems had obviously to do with the late effects of former polio. Her doctors had not found an answer or a reasonable explanation. This was — and often still is — the typical experience of polio survivors when decades after the acute disease and successful recovery, forgotten difficulties turn up again.

Now she wanted to know how I became interested in the subject, and why, as a science writer, took up such an “exotic” theme. The first information and the stimulus to deal with it had come from my doctor more than 10 years ago. The rest was own involvement.

Having had paralytic polio in 1928 and quite a history of nearly full recovery after a muscle transferral, problems came decades later from the damages to the paralyzed leg from an accident. In the '70s an odyssey through university hospitals began. Different suggestions for operations were made. But in view of the long-standing and wide-spread muscular-skeletal dysfunctions with severe joint deformities, I regarded them as too risky. Finally, in 1980, I met an orthopedic surgeon who, for the first time, noted the complexity. He suggested bracing; the idea of more surgical “reconstruction” was discarded. Since then, an independent and active, though changed life gradually developed again.

In 1982, my doctor — a famous expert of holistic rehabilitation — showed me papers brought from a medical congress in the U.S. that dealt with a 1981 symposium in Chicago. Under the title “What Ever Happened to the Polio Patient?” progressing functional losses had been discussed. Since they were unexpected and, at that time, somehow incompatible with the accepted philosophy of a stable, physical condition gained after acute poliomyelitis, many doctors as well as family members doubted deteriorations as reported.

However, Gini Laurie, from St. Louis, had strongly pleaded for the conference, attended by nearly 200 persons from five countries. Panel participants included medical as well as research and engineering experts

in various fields, officers from public health and social agencies, and, of course, polio patients. Already for 25 years she had been the person to whom people with severe disabilities from polio, other neuromuscular diseases, and from accidents would talk or write to. Her organization, Rehabilitation Gazette, with a journal of the same title, had developed into a well-known forum. (Since 1984, the name has been Gazette International Networking Institute — G.I.N.I.)

Having lost three siblings herself to polio, Gini visited and cared for paralyzed children, youths, and adults during the time of catastrophic epidemics in the Toomey Pavilion, part of Metropolitan General Hospital in Cleveland, Ohio. It was one of 16 respiratory centers established and supported by the private foundation, March of Dimes. Most of them were closed when the dramatic success of mass vaccinations against poliomyelitis in the early '60s became obvious. The foundation set other priorities.

Gini Laurie and friends had already looked to bring ventilator-assisted patients home to live with their families. Physicians and therapists, social workers, teachers, psychologists, as well as engineers and industry managers became interested to cooperate. Special equipment of all kinds was needed — from different beds to lighter ventilators which were not so difficult to maintain. Finally, home care of severely

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Update ...

Several readers have asked about the article “Unintended Casualties in the War on Polio” in the June 6, 1993, *Philadelphia Enquirer*, and the segments on *American Journal* and *Front Page* regarding individuals who contracted polio from the vaccine.

Polio Network News, (Winter 1992, Vol. 8, No. 1), mentioned the vaccine ruling cited in all of the above. “... the essence was that the government is liable for injuries caused over several decades by oral polio vaccine.

“The case asserted that the Federal Division of Biologics Standards (DBS) — now known as the

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physically disabled persons proved to be not only practical when duly organized, but also less expensive than hospital care. And, after all, Gini and her publication — *Rehabilitation Gazette* — had kept polio survivors with experience from respiratory wards in touch with each other, offering advice and solutions for difficulties when living at home.

Letters from polio survivors she had received in the late '70s alerted her to the new health problems. At the time of the Chicago conference, one could only guess for the causes of symptoms such as severe fatigue, exhaustion, muscle and joint pain, new weakness in the affected, as well as formerly not affected, muscles. Chronic overburdening of parts of the body from abnormal motions, abnormal forces on muscle, connective and ligament tissue, and the skeletal system as a result of polio, and the endeavors to compensate for malfunctions, obviously contributed to the new situation.

Based on experiential reports by patients and health professionals, the participants in the Chicago conference advocated for more research in many fields — from epidemiology to biochemistry to rehabilitation. Suggestions for polio patients and their families were discussed. However, questions as to exact diagnostic criteria and special therapies were not answered, neither were questions as to early warning signs.

In her address to a medical congress in 1982, Gini Laurie stressed the pioneering work of the respiratory and polio rehabilitation centers. They had developed the team work concept evident today in all medical institutions, which integrates the patient and his family into the rehabilitation process. The polio patients have become "role models for people who master life with severe disabilities and, with technical devices and personal assistance, do productive work ... Despite the disease and its aftermath many continued school and professional education. Today they are lawyers, physicians, professors, psychologists, therapists, writers, business managers. Nobody needs to speculate any longer whether occupational rehabilitation or university studies are worthwhile for people with severe disabilities."

"A great personality! You should meet her," my doctor said upon his return from said meeting, and handed me, among other papers, an invitation for the next conference (1983) in St. Louis. My reluctance in view of now limited physical abilities was not accepted. "In America you will get help everywhere." Right he was — and Gini Laurie, in a letter, encouraged me. Undemonstrative and self-evident helpfulness in America was experienced in many different situations and regions of the country in years to come.

The 1983 conference in St. Louis turned out as a very important event for my future life — first of all, because I met Gini. Secondly, it was new for me to meet and talk to so many polio survivors from

America and overseas countries with significant disabilities in a non-hospital environment. Thanks to their ventilators, mobile devices, and attendants, they were free human beings living independently.

Upon my return to Germany, I began reading everything available about polio and its late effects, including scientific documentation. An outstanding event of the 1985 conference was the address by Dr. Albert Sabin. In 1987, the "harvest" from medical lectures and interviews with noted physicians was quite extensive. As a result, several articles were published in nationwide daily newspapers and in a medical newspaper. Information to readers from various levels of society had started and has been going on.

Up to now, the last congress about polio late effects, combined with a symposium of independent living, was in 1989. Despite her serious illness, Gini Laurie had prepared every detail. And not only that: she was wheeled into the various conference rooms on a comfortable couch, she appeared for important lectures in forenoon as well as afternoon hours — encouraging, and, if necessary, setting things in perspective. She was deeply irritated by the violent suppression of the student's revolt in China during those days, and much concerned for two participants from Beijing who were to return to their families. Three weeks later, on June 28, 1989, Gini Laurie died, shortly after her 76th birthday — respected, beloved, and mourned by many people in the world. ■

International Polio Network

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The Sixth International Post-Polio and Independent Living Conference

The Sixth International Post-Polio and Independent Living Conference will convene June 16 through 19, 1994 in St. Louis, Missouri. The program has not yet been finalized, but the Thursday morning session will be for first-time conference attendees. Thursday afternoon plenary session topics will include Status of Polio Today; Aging with Polio: Definitions and Distribution; Solutions for Orthopedic Problems. The Friday morning topics will include Post-Polio Corrective Surgery: Then and Now, and New Breathing and Swallowing Problems. On Friday afternoon attendees will be able to choose from a variety of topics including suggestions for energy conservation and enhancing lifestyle, discussion of disability as it relates to the future and family, and a special forum for ventilator users. Saturday morning will also provide attendees an opportunity to choose from a variety of sessions relating to health care reform, chronic pain, face masks, other therapies, Social Security, ADA, etc. Saturday afternoon the attendees will meet in a plenary session to discuss post-polio research and challenges facing individuals with a disability.

Thursday evening will feature a presentation by Al Siebert, an ex-paratrooper with a PhD in psychology from the University of Michigan. Dr. Siebert has studied survival and interviewed survivors for over 40 years and is nationally known for his survivor personality research. His book, *The Survivor Personality* (ISBN: 0-944227-06-6), was published in 1993.

Friday evening dinner will not be included in the meal package. For advanced information about the City of St. Louis' scheduled events, restaurants, etc., contact the St. Louis Convention and Visitors Commission's tourism information (800/888-FUN1). The St. Louis Cardinals baseball team will be playing the Pittsburgh Pirates, Thursday, Friday, and Saturday nights, and Sunday afternoon. For advanced tickets call Busch Stadium (314/421-3060).

The site of the conference will be St. Louis Marriott Pavilion Downtown, One Broadway, St. Louis, Missouri 63102. The Marriott is a reasonably priced hotel which meets the minimal ADA requirements. Detailed information about the rooms will be made available in the registration packet to assist you in booking your room. Due to the large number of attendees with disabilities, your cooperation will be needed.

Program information, as well as the registration form and hotel registration information, will be published in the January *Rehabilitation Gazette*, and the February *Polio Network News*. ■

Update ... Continued from page 1

Office of Biologics Research and Review — violated its own regulatory standards by not following its own neurovirulence standards and also by allowing attenuated (weakened) vaccine viruses to be put through more tissue cultures than the regulations allowed during manufacture.”

At that time the government was appealing the decision.

Polio Network News contacted Stanley P. Kops, Esq. and Marc S. Moller, Esq. for an update.

POLIO NETWORK NEWS: *What is the status of the appeal?*

MR. KOPS/MR. MOLLER: The Government lost the appeal. In a unanimous decision, the Court of Appeals for the Fourth Circuit affirmed the Lower Court decision in all respects.

POLIO NETWORK NEWS: *How many individuals were involved in the case against the Government, and what has been the outcome for them?*

MR. KOPS/MR. MOLLER: In the lawsuit against the Government, there were seven plaintiffs, four children and three adults. All but two of the cases have been settled by the Government. The two remaining cases are in the process of either being settled or will be tried.

POLIO NETWORK NEWS: *Were vaccine companies involved?*

MR. KOPS/MR. MOLLER: Each of the seven individuals involved in the lawsuit with the Government have already brought a lawsuit against the drug manufacturers. They all have settled with the manufacturers.

POLIO NETWORK NEWS: *Are the regulatory standards for polio vaccine being met today?*

MR. KOPS/MR. MOLLER: The Government, immediately upon the April 1991 decision of the Trial Court, amended the Regulations so that what was impermissible became permissible.

POLIO NETWORK NEWS: *What has this legal action accomplished?*

MR. KOPS/MR. MOLLER: In the broad sense, this action accomplished that the rule of law is supreme; that the Government cannot violate laws without having to pay the victims who are injured as a result of the violations.

POLIO NETWORK NEWS: *Parents who have heard about this may be reluctant to have their children immunized. There are some scary consequences of that scenario. What would you say to parents?*

Continued on page 5

Readers Respond



◆ "I was diagnosed with post-polio syndrome in 1986. My job was that of a special education teacher. I was able to work out a system with the school principal to take time off for rests on a periodic basis. This greatly helped my physical condition! However, it was very hard to handle youngsters with physical disabilities and still meet my own medical needs. Finally, I made the decision to give up a full time job and try part time work.

"My first part time job was in a store. Once again I expressed my medical needs. The manager was willing to give me four or five hours per day of work with the weekends off to renew my strength. I also was put on a job that didn't require much lifting.

"As time went on I really wanted to work at a job that dealt more with helping people. I currently work on a part time basis in a nursing home as a speech therapy aide. This past year my employer wanted to increase my time by five hours per week. I hesitated but then decided to take on the extra time but not without asking for a reasonable accommodation. We agreed on the five extra hours, if I could put them in on days that I felt rested and up to it. This arrangement has been working well for several months now.

"I have found that it pays to express what your needs are the first time you meet with a prospective employer. We all must work hard to provide the best reasonable accommodations for our own individual situations. I urge all readers to continue making employers aware of how important reasonable accommodations can be in order to retain a valuable employee." **Sharon, New York**

◆ "I enjoy your publication very much as I had polio in 1910 at the age of eight months; walked at age three; had surgery on my legs at age 11. Polio affected only my legs, and I walked with a crutch leading an active life, including college, employment, marriage, and two children.

"However, in my middle '50s, and from then on, I began to feel weakness in my legs and fell more. My doctor called it aging, but it seemed to me I was aging earlier than I should. It was such a relief to me when I read about post-polio problems and to later receive your various publications.

"I live in a remote rural area and have not been evaluated by a specialist. But, from my reading, I have learned to spare myself physically and to anticipate certain changes. Now I use two crutches when I walk and go out in a wheelchair.

"I live alone, now widowed, but my daughter lives next door so, except for not being able to drive a car, as I did formerly, I can still be independent. That is very important.

"I am writing this to let you know that there was polio before the large polio epidemics in the '40s and '50s and to thank you again for the good work you are doing, and the hope and help you give." **Elizabeth, California**

◆ **Polio Network News**, Summer 1993, (Vol 9, No. 3), asked readers to send in names of qualified and experienced orthotists. We received the following:

Thomas E. Beall, CPO, Valley Orthopedic Inc., 3520 E Shield, #102, Fresno, CA 93726 (209/221-1933).

Robert Bird, Orthotist, Fresno Orthopedic Company Inc., 7575 N. Del Mar, Suite 101, Fresno, CA 93711 (209/431-7045).

J. Paul Reid, CPO, Reid Medical Systems Inc., 1543 San Marco Blvd., Jacksonville, FL 32207 (904/396-0616).

Mark J. Yanke, CPO, Yanke Bionics Inc., 303 W Exchange St., Akron, OH 44302 (216/762-6411).

Jeffrey Dietz, CO, OTR, Moss Rehabilitation Hospital, 12th and Tabor, Philadelphia, PA 19141 (215/456-9375).

John W. Potter, CPO, Cedar Creek Orthotics and Prosthetics Inc., 2716 W Main (Highway 85), Gun Barrel City (1 hour SE of Dallas), TX 75147 (903/887-5544).

◆ "I had polio in 1965 and am now 37 years old. I would like to communicate with polio survivors my age who are having problems. I do not look disabled, and I don't seem to fit anywhere. The only good thing is that a physician can't tell me it's only aging." **Tania Mahon, 2713 N.E. 8th, #1, Wilton Manors, FL 33334**

◆ "I would like to correspond with other post-polio individuals." **Mrs. Michael Nauyoks, 816 Glenwood Ave., Waukegan, IL 60085.**

◆ **J. G. Johnson, 550 NW Merrie Dr., Corvallis, OR 97330 (503/737-1229)** is interested in purchasing a used, but working, Multilung.

◆ **Rodney Barth, 824 W Walnut, Chatham, IL 62629** has a PLV-100 with minor problems he would like to sell.

◆ "I was diagnosed as having Candida infection, unrelated to post-polio syndrome, was treated with Capricin and experienced small improvements in my post-polio symptoms. Nystatin was later prescribed. It produced improvements in my ability to think, but a worsening of pain, weakness, and muscle twitching. An alternative natural treatment, oil of oregano, acidophilus, and molybdenum, eliminated Candida digestive symptoms and dramatically improved chronic fatigue, pain, weakness, thinking and memory." **Stephan, Oregon**

◆ "I use crutches and a leg brace to get around, but also use a wheelchair a lot of the time to save energy and get relief from wearing the brace. A few months ago my muscle (and joint) pain was so severe that I used the wheelchair more.

"I am writing to relate the relief I've gotten from those muscle aches (spasms) and joint pain. I have hypoglycemia (low blood sugar) and noticed over a period of time the correlation of severe muscle spasm pain and overall fatigue with hypoglycemic attacks.

"I have stopped using sugar in all forms (fructose, sucrose, lactose, etc., honey, and corn syrup), and my hypoglycemic problem is under control. My other problems have greatly reduced, and I'm able to maneuver with my brace and crutches again.

"Some indications of hypoglycemia are: fatigue, confusion, headache (after consuming sugar), being constantly hungry or craving sweets, and irritability.

"Everyone with polio problems doesn't have hypoglycemia, but if you suspect that you might, I encourage you to check it out." **David, Texas**

◆ "Your readers may be interested in getting a copy of excellent articles on Franklin D. Roosevelt that appeared in *Public Welfare* magazine, (Spring and Summer 1984). Copies of Part I and Part II are available from the American Public Welfare Assn., 1225 Fifteenth St., NW, Washington, DC 20005 (202/293-7550). Articles are \$2.75 apiece pre-paid." **Sharon, Texas**

◆ "I am a polio survivor living in Florida where the State has done a great service to individuals who require restricted parking privileges. It has eliminated the symbols on the rear of the vehicle and has begun issuing a placard to be hung on the rear view mirror only when parked. I feel it would be a great service to all individuals with a disability if this would be adopted nationwide. I urge readers to contact their appropriate officials and news media requesting them to adopt this program nationally." **Dorothy, Florida**

◆ DID YOU "mean" TO BE TO BE SO MEAN?

"Adults with disabilities who speak out without checking for the disabled parking sticker in my vehicle window are making me angry," said the young, pregnant mother of three.

Her eldest, a child of six, is physically disabled with Cerebral Palsy. He requires a good deal of assistance and mechanical aids.

"Four times in the last month, I've gotten rude comments from adults with disabilities who feel called upon to chastise me for using a disabled parking spot. They, of all folks, should KNOW how hard it was to get a disabled parking permit."

She paused for breath, obviously seeking to control her temper, then continued.

"My child qualifies for 3 of the 4 categories for getting a disabled parking permit in the state of Washington:

- 1- oxygen dependent
- 2- can't walk 100-200 feet unassisted without resting
- 3- needs assistive aids (prosthetic)
- 4- or has wheelchair

"I don't want my child to grow up to think his disability gives him the right to be rude to other people (disabled or not!) especially in public."

At my sympathetic nod, she went on. "You know, I make it a point of honor to never even use those parking spots unless my son is with me.

But by the time my disabled child exits the vehicle I've already had a severe, unwarranted tongue lashing from a total stranger.

Now why should I feel like I even owe an explanation to the very people who should KNOW better?"

We all need to realize that our personal disability or our adult status does not mean we are the only ones entitled to a disabled parking permit and we should remember to act or SPEAK accordingly. Many forms of disability

are not readily apparent to the naked eye. Some are hidden disabilities.

There are 43 million Americans with disabilities.

I think we need to be kinder to one another.

by LaVonne Schoneman, reprinted from: HOW TO COPE, More Practical Choices for Polio Survivors & OTHERS, Copyright ©1993

LaVonne Schoneman, 16734 — 8th NE, Seattle, WA 98155, USA, (206/362-0627), has published #1 Practical Tips for Polio Survivors, #2 MORE Practical Tips for Polio Survivors, #3 More Practical CHOICES for Polio Survivors, and #4 More Practical Tips & Choices for Polio Survivors & OTHERS.

The books are priced as follows: \$7.00 for 1 book, \$12.00 for any 2 books, \$19.00 for any 3 books, \$24.00 for all 4 books, USA postage & handling FREE; Foreign orders add \$3.00. ■

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MR. KOPS/MR. MOLLER: There is a safe alternative in the killed vaccine. This should be discussed with the administering physician so that the parent understands fully the benefits of the killed vaccine, the benefits of the live vaccine, and the risks involved in the live vaccine.

RESOURCES:

The National Vaccine Information Center (NVIC) provides information to the public on vaccines and may be contacted by writing to NVIC/DPT, 512 W. Maple Ave., #206, Vienna, VA 22180 or by calling 1-800-909-SHOT.

New Voice/FAX Service is Available from CDC for Immunization Information — The Centers for Disease Control and Prevention (CDC) and the National Immunization Program (formerly the CDC Division of Immunization, National Center for Prevention Services) have implemented a 24-hour, seven-days-a-week automated FAX and voice system for easy caller access to immunization and travel information. The new service provides answers to questions most frequently asked by health care professionals and parents.

The FAX material contains the most consistent, comprehensive and up-to-date information regarding immunizations, including those needed for foreign travel. The system's information ranges from brief summaries suitable for the general public to the most technical ACIP statements for each vaccine.

Simple to Use — The CDC FAX Information Service provides step-by-step phone instructions to guide the caller to receive either a directory of available topical information or specific FAX documents. When calling this service, one should have an available facsimile telephone number handy.

Direct Access to the Immunization Voice Information System: Dial 404/332-4553 for information specific to immunizations, and select the topic of interest and method of delivery: FAX, mail or voice; or

Dial Direct to the CDC FAX Information Service: Dial 404/332-4565 to reach the CDC FAX Information Service, and request the immunization directory; or

Access the CDC Voice Information System: Dial 404/332-4555 for entry into the CDC-wide voice system, which contains other topics as well as immunizations. ■

NUTRITION ODDS AND ENDS

TERMS YOU SHOULD KNOW

DIETARY FAT

fat we eat — solid and liquid
limit to less than 30% of your total calories

POLYUNSATURATED FAT

liquid at room temperature
from plant sources

SATURATED FAT

solid at room temperature
from animal sources
hydrogenated oils
coconut oil
palm oil

HYDROGENATION — the process in which liquid fats are changed to solid fats, making the fat saturated.

CHOLESTEROL

waxy substance found in blood
made by humans
found in animal products only
limit to less than 300 mg per day

TRIGLYCERIDES

fat in food and our blood
converted in liver from excess sugar and alcohol

HYPERTENSION

 — high blood pressure

CORONARY ARTERY DISEASE — a condition in which the arteries (blood vessels) in the heart become blocked with fatty deposits (plaque). A diet high in cholesterol and saturated fat is a factor in the formation of these deposits.

Match your daily calorie intake on the left with the grams of fat on the right. That's the maximum grams of fat you can have each day and still remain within the 30 percent of calories from fat recommended by the federal government.

Daily calorie intake	Maximum daily fat intake for a prudent diet
1200	40 grams
1500	50
1800	60
2000	67
2200	73
2400	80
2700	90
3000	100

What Is Your Healthy Weight?

The truth is: there's no precise answer. Healthy weight depends on three key factors: 1) how much body fat you have, 2) where your body fat is located, and 3) whether you or your family have weight-related health problems. You can, however, get a general sense of your body weight with these guidelines.

Weight for Height

A healthy weight actually is an individual matter. So the updated height-weight chart on this page offers a weight range for someone your age and height. People with more muscle and larger bones usually fit the upper end of the range; both muscle and bone tissue weigh more than body fat. Studies indicate that you can weigh a little more if you're age 35 or older without adding to your health risk.

Now check your weight against the height-weight chart. Are you within a health range? Health problems

can be linked to weighing more — or less — than the weight indicated in the range.

Suggested Weights for Adults

Height ¹	Weight in pounds ²	
	19 to 34 years	35 years and over
5'0"	97-128	108-138
5'1"	101-132	111-143
5'2"	104-137	115-148
5'3"	107-141	119-152
5'4"	111-146	122-157
5'5"	114-150	126-162
5'6"	118-155	130-167
5'7"	121-160	134-172
5'8"	125-164	138-178
5'9"	129-169	142-183
5'10"	132-174	146-188
5'11"	136-179	151-194
6'0"	140-184	155-199
6'1"	144-189	159-205
6'2"	148-195	164-210
6'3"	152-200	168-216
6'4"	156-205	173-222
6'5"	160-211	177-228
6'6"	164-216	182-234

¹Without shoes.

²Without clothes.

³The higher weights in the ranges generally apply to men, who tend to have more muscle and bone; the lower weights more often apply to women, who have less muscle and bone.

Source: Derived from National Research Council, 1989.

Measure for Measure

For adults, body shape is as important to health as body weight. A so-called "beer belly" may be riskier than you may think. Too much body fat around the "middle" — your abdomen — may increase your risk for heart disease and diabetes, more than fat around your hips and thighs.

Check your body shape. If the mirror doesn't reflect a clear picture of the shape you're in, get out the tape measure!

Measure your waist near your navel — but don't pull in your stomach!

Next, **measure around the widest place on your hips.**

Now figure your waist-to-hip ratio. Divide your waist measurement by your hip measurement. A ratio that is close to — or more than one — puts you at greater risk for certain health problems, such as heart disease.

Health Problems?

Does your family have a history of weight-related health problems? High blood pressure, heart disease, stroke, certain cancers and other types of illness are linked to excess body fat. If you have any of these problems, ask your physician to recommend the weight that's best for you.

Achieving — and maintaining — your healthy weight may be one of your best strategies for keeping fit. In fact, keeping your body lean is healthier than recurring cycles of weight gain and weight loss. How do you do that? Eat a balanced diet from all Food Groups — Milk, Meat, Fruit, Vegetable and Grain; control your calorie intake; and avoid too many high-fat, high-calorie extras. Control the urge to eat when you feel bored or stressed.

RESOURCES:

Live Well, The Low-Fat/High-Fiber Way — the American Health Foundation Food Plan is 40-page booklet available from the American Health Foundation for \$4.50 postpaid. An eight-page bimonthly newsletter is also available for \$9.98. Contact: American Health Foundation, 1 Dana Road, Valhalla, NY 10595.

By calling the American Dietetic Association nutrition hotline (800/366-1655) one can obtain the names of three dietitians in one's area.

Contact National Dairy Council, O'Hare International Center, 10255 W. Higgins Rd., Suite 900, Rosemont, IL 60018-5616 (708/803/2000, FAX 708/803-2077) for information and location of regional/local office. Many publish a newsletter.

The American Seafood Institute's *Seafood Hotline* (800/328-3474) has experts available weekdays from 9 a.m. to 5 p.m. Eastern Standard Time to answer questions about the buying, storage, preparation, and nutritional profile of seafood. Callers can also purchase seafood cookbooks. To receive a list of the books the Hotline offers, send a self-addressed, stamped, business-size envelop to ASI, 406-A Main St., Wakefield, RI 02879.

National Yogurt Association, 1764 Old Meadow Lane, Suite 350, McLean, VA 22102.

For a free booklet about dinnerware for persons with disabilities, write to: Alternative Stoneware, P.O. Box 2071, Charleston, WV 25327-2071.

To order the free publication, *What You Should Know About Lead in China Dishes*, send your name and address to the Environmental Defense Fund, 257 Park Avenue South, New York, NY 10010.

The following four publications can be ordered from R. Woods, Consumer Information Center - 3D, P.O. Box 100, Pueblo, CO 81002 (add \$1.00 service fee):

1. *Eating to Lower Your High Blood Cholesterol.* A guide to

help you choose, go easy on, and decrease certain foods. Includes menus, guidelines, cooking tips, and comparison charts. 53 pp. (1987. NIH) 116Z. \$2.00.

2. *Food Facts for Older Adults* ... suggests how to improve your diet with 17 simple recipes and teaches you how to modify your own for better health using less fat, cholesterol, and sodium, and more calcium, vitamin D, and fiber. 68 pp. (1993. USDA) 15 oz. \$4.00.

3. *The Food Guide Pyramid* ... will help you choose what and how much to eat from each food group to get the nutrients you need. 30 pp. (1992. USDA) 117Z. \$1.00.

4. *Thrifty Meals for Two.* A guide on how to shop for and prepare hearty, nutritious, and economical meals. Includes menus and recipes. 69 pp. (1985. USDA) 118Z. \$2.50.

Ohio Distinctive Software, Columbus, OH (614/459-0453) offers four nutrition computer programs for just \$8 (\$11 post-paid). Available for both IBM and Macintosh computers, on either 5.25- or 3.5-inch floppy disks:

1. *Executive Diet Helper*, counts calories, fat, and cholesterol both for individual foods and for entire meals.

2. *Weight Loss Planner*, quickly calculates how long it will take you to reach your weight-loss goal, either with or without exercise.

3. *Menu Planner*, creates daily menus for any calorie level, and it can modify the menus for special needs, such as those of pregnancy and breast-feeding, diabetes, and milk or cheese sensitivity.

4. *Food Label Analyzer*, takes information you provide from food labels and calculates the percentage of calories from fat along with percentages of the RDAs the food provides.

Eating Smart: ABCs of the New Food Literacy (ISBN 0-025-597-72-8), Jeanne Jones; MacMillan, New York, hardcover, \$17.00 (800/257-5755). A 140-page primer covering all of the fundamentals of healthful eating, by Jeanne Jones who writes the "Cook It Light" syndicated newspaper column.

The Four-Course 400-Calorie Meal Cookbook (ISBN 0-809-240-58-0), Nancy S. Hughes; Contemporary Books, Chicago, softcover, \$10.95 (312/782-9181, ask for customer service). The book contains recipes for entrees, salads, vegetable dishes, and desserts. Choose any salad, vegetable, entree, and dessert dish, and the result is a meal with no more than 400 calories.

Skinny Soups (ISBN 0-940-625-41-5), Ruth Glick and Nancy Baggett; Surrey Books, Chicago, softcover \$12.95 (800/326-4430). Offers recipes for more than 100 soups, each of which contains less than 30% of its calories from fat.

New Dieter's Cook Book (ISBN 0-696-019-74-4), Better Homes and Gardens, Meredith Corporation, Des Moines, hardcover, \$29.95 (800/678-8091). Contains 427 recipes designed to help individuals control their weight, fat, and cholesterol intake.

How to Eat Like a Southerner and Live to Tell the Tale (ISBN 517-576-83-X). Courtney Parker; Clarkson Potter, New York, hardcover, \$20.00 (800/733-3000). Offers more than 150 down-home, yet reduced-fat and reduced-calorie dishes.

The FDA Consumer is published ten times a year by the U.S. Food and Drug Administration, the consumer protection agency responsible for food, drugs, medical devices, and other products. Clearly written for lay audiences, it helps readers understand the latest research. To order a subscription to the *FDA Consumer*, indicate List ID FDAP, and send your check or money order for \$15 per subscription. Or send your VISA or MasterCard number and expiration date to: Superintendent of Documents, P.O. Box 371954, Pittsburgh, PA 15250-7954. Price includes shipping and handling.

Continued on page 8

Supplements

READ THE LABEL! Take a careful look at the ingredients of any supplements you take. Talk with your doctor or a nutrition expert about each of these ingredients: Are they necessary? Are they safe, given the dose you ingest, your general health and any medications or other supplements you may take?

Be aware that taking "megadoses" of certain vitamins and minerals can be dangerous. Compare the ingredients in the products you buy with the table below, adapted from one prepared by the National Research Council. It will tell you at a glance the doses at which specific nutrients can become potentially toxic.

NUTRIENT	POTENTIALLY TOXIC DAILY DOSES
Vitamin A.....	25,000-50,000 IU
Vitamin D.....	50,000 IU
Vitamin E.....	1,200 IU
Vitamin C.....	1,000-5,000 Mg
Thiamin (B-1).....	300 Mg
Riboflavin (B-2).....	1,000 Mg
Niacin (B-3).....	1,000 Mg
Pyridoxine (B-6).....	100-200 Mg
Folacin.....	400 Mg
Biotin.....	50 Mg
Panthothenic Acid.....	1,000 Mg
Calcium.....	12,000 Mg
Phosphorus.....	12,000 Mg
Magnesium.....	6,000 Mg
Iron.....	100 Mg
Zinc.....	500 Mg
Copper.....	100 Mg
Fluoride.....	4-20 Mg
Iodine.....	2 Mg
Selenium.....	1 Mg

The following is reprinted from *Orphan Disease Update*, Vol. XI Ed. 1, National Organization for Rare Disorders, NORD, P.O. Box 8923, New Fairfield, CT 06812:

NORD (National Organization for Rare Disorders) has been mentioned in several newspaper and magazine articles recently about the "nutritional supplement" controversy, and NORD's Executive Director, Abbey Meyers, appeared on two June segments of Dan Rather's CBS News discussing this topic.

Because certain inborn errors of metabolism are treated with large doses of vitamins, minerals, or other nutritional supplements that are available over-the-counter, NORD has become increasingly concerned about the quality of these products.

The Food & Drug Administration (FDA) does not regulate the manufacture of dietary supplements, as they do drugs. Therefore, consumers have no guarantee that when they buy one of these products they are getting exactly what they paid for. Furthermore, health insurance companies and even state Medicaid systems have refused to reimburse for some prescription versions of these products because they insist that nutritional supplements are available without prescription.

A recent Duke University study published in the *Journal of Clinical Research and Regulatory Affairs* (10 [2], pgs. 71-80, 1993), examined a prescription version (regulated by the FDA) of the orphan drug, L-Carnitine, with twelve brands of food supplement versions that are available without prescription.

Of the twelve supplement versions of L-Carnitine tested, seven did not disintegrate within the time needed for the human body to benefit from the product, and most of the products contained less than 60% of the amount of L-Carnitine listed on the label. Indeed one brand contained no L-Carnitine at all, and one brand had undetectable amounts of L-Carnitine.

The scientists found "some products showed considerable variation between samples from different preparations (brands) supplied by one manufacturer, and in some cases between samples from the same bottle." This is probably because the FDA does not require quality controls in the manufacture of supplements, nor do they test the dissolution, disintegration, and content of these products.

If a healthy person takes nutritional supplements, often to prevent a disease instead of treating one, perhaps the content and dissolution of the pills or capsules doesn't really matter. But when insurers tell people with rare diseases to purchase unregulated health food versions of a supplement to treat a serious or life threatening disease, lives may be put in danger.

For people with valid medical need for nutritional supplements, this is a very serious problem that calls for mandatory government regulation of the health food industry. However, the supplement industry is advocating for a law that would permanently prohibit FDA from regulating the manufacture of these products, and it is encouraging people to write to Congress by distributing lobbying materials through health food stores. Primarily, their misinformation campaign says that unless the "Hatch-Richardson Act" is passed by Congress, the FDA will require people to provide a prescription for vitamins. This is not true! FDA has no intention of requiring prescriptions for nutritional supplements. The agency wants only to protect consumers by assuring that the supplements you buy are safe and contain the ingredients that are listed on the label.

We feel the American consumer, whether he/she buys a nutritional supplement for valid or invalid medical reasons, should get exactly what they pay for. But FDA is not empowered under current law to protect the public from manufacturers who are getting rich by avoiding government oversight. NORD feels that Congress should defeat the Hatch-Richardson Act and pass a law instead to empower FDA to regulate these products. ■

Source: *Orphan Disease Update*, Vol. XI Ed. 1, National Organization for Rare Disorders, NORD, P.O. Box 8923, New Fairfield, CT 06812.

Dear Friend:

You have been selected to participate in a research study to determine if survivors of polio experience urinary incontinence, and if so, to what extent urine leakage is a problem. Your participation in this survey is entirely voluntary. Your consent to participate is granted by completing the questionnaire below and returning it to the investigator.

Approximately ten million people, in the United States alone, have difficulty with bladder control. Estimates are that only one in twelve seek assistance or report this problem. Failure to seek help can result in decreased social interaction, loss of self esteem and subsequent loss of independence. The purpose of this survey is to determine how widespread this problem is among survivors of polio. Information obtained from this study will be used to determine future research needs, as well as provide additional knowledge regarding health needs of individuals who have survived polio.

The 66 item questionnaire below will take about 20 minutes to complete. After completion, return the questionnaire to the address on the back of this form by January 1, 1994. Nothing else will be required of you. All information will be reported as group data. Please do not put your name on the questionnaire. Thank you for your interest and willingness to participate.

Questionnaire for Survivors of Polio

(Circle your answers and/or write your answer in the blanks provided)

1. Country of residence? _____ Zip code (if in USA) _____
 2. Gender: (a) Male _____ (b) Female _____ 3. Age: _____ 4. Height: _____ Weight: _____
 5. Age when you first contracted polio? _____ (years of age) and/or _____ (months of age)
 6. When were you diagnosed with polio? Year _____

YES NO 7. Did you have any bladder symptoms (problems) during the time you had polio?
 If yes, describe these _____

YES NO 8. Have you had any abdominal or pelvic surgeries?
 If yes, list type of surgery, or surgeries, and approximate year: _____

Circle the number of any of these health problems you now or have ever had:

- | | | |
|----------------------|-------------------------------|--|
| 9. Diabetes | 14. Bladder/kidney Infection | 19. Heart Disease |
| 10. Cancer | 15. Kidney Disease | 20. High Blood Pressure |
| 11. Lung Disease | 16. Multiple Sclerosis (M.S.) | 21. Stroke |
| 12. Vision Problems | 17. Parkinson's Disease | 22. Poliomyelitis(list type if known): _____ |
| 13. Walking Problems | 18. Arthritis | 23. Spinal Cord Injury |
| | | 24. Scoliosis |
25. Other: _____

26. List the medications you take on a daily basis, including both those prescribed by your physician or nurse practitioner AND medicines you purchase at the store without a prescription, such as aspirin: _____

27. Do you use any of the following: (Circle any/all that you use and circle amount of time used)
 (A) cane (B) walker (C) wheelchair (D) brace(s) (E) orthotic devices (built up shoe(s), etc.) (F) motorized chair/cart?
 (a) Seldom (c) Most of the time
 (b) Occasionally (d) All of the time

(Circle your answers and/or write your answer in the blanks provided)

- YES NO 28. Are you physically able to go out of your home?
 YES NO Do you require assistance?
 YES NO 29. Can you stand for more than 15 minutes?
 YES NO 30. Do you need help with your shower or bath?
 YES NO 31. Do you need help getting dressed?
 YES NO 32. Do you need help getting up from a chair?
 YES NO 33. Do you take a water pill (diuretic)?
 YES NO 34. Do you leak urine when you cough or sneeze?
 YES NO 35. Do you leak urine when you bend or lift?
 YES NO 36. Do you ever get sudden urges to empty your bladder followed by loss of urine?
 YES NO 37. Do you have trouble getting to the bathroom in time to avoid urine leakage?
 YES NO 38. Do you leak urine as a result of not getting to the bathroom in time?
 YES NO 39. Do you "dribble" urine?
 YES NO 40. Do you have trouble starting urination or the stream of urine?
 YES NO 41. Do you leak urine continuously?
 YES NO 42. Do you feel that you empty your bladder completely when you go to the bathroom?
 YES NO 43. Do you get up during the night to go to the bathroom? If yes, how many times/night? _____
 YES NO 44. Do you leak urine while you sleep?
 YES NO 45. Do you wear a catheter tube in your bladder?
 YES NO 46. Do you limit fluids you drink because of urine leakage?
 YES NO 47. Do you drink beverages with caffeine, such as coffee, tea, or colas? How many cups, glasses or cans/day _____
 YES NO 48. Do you drink beverages that contain alcohol? If yes, list the type (beer, wine, etc.) _____
 Approximately how many ounces each day? _____

PLEASE CONTINUE SURVEY ON THE BACK OF THIS PAGE

QUESTIONS FOR WOMEN

49. Number of pregnancies? _____ Number of vaginal deliveries _____ Cesarean deliveries _____

YES NO 50. Has menopause (change of life) occurred? _____ If yes, at what age? _____

YES NO 51. Do you take hormone replacement(s) such as oral estrogen or wear an estrogen patch?

If yes, indicate what type of hormone replacement you use: _____

QUESTIONS FOR MEN

YES NO 52. Have you had prostate problems?

YES NO 53. Have you had prostate surgery? If yes, what type? _____

YES NO 54. If yes, did you have urine leakage after the surgery?

YES NO 55. Do you have leaking of urine now? If yes, how often _____

IF YOU CURRENTLY HAVE URINE LEAKAGE OF ANY KIND, PLEASE ANSWER THE FOLLOWING QUESTIONS:

56. How often does urine leakage occur?

- (a) continuously (b) daily, several times (c) 1-2 times/week
-
- (d) 3-6 times/week (e) 1-2 times/month (f) only a few times/year

57. Check one of these descriptions to rate your urine leakage problem: (a) Mild (b) Moderate (c) Severe

58. How much urine comes out when leakage occurs? ENOUGH TO: (Circle your answer below)

- (a) dampen underwear (b) soak underwear and clothing only
-
- (c) soak underwear, but not clothing (d) soak underwear, clothing and wet furniture

59. How long have you had this problem? Years _____ and/or Months _____

YES NO 60. Do you use any products to manage the wetness?

If yes, please list what products you use? _____

YES NO 61. Are you satisfied with the way you manage leakage?

YES NO 62. Have you discussed this problem with a health professional?

If yes, indicate which one(s):

- (a) doctor (b) nurse (c) Other (specify) _____

63. About how much money do you spend each WEEK on products to manage this wetness problem? \$ _____

YES NO 64. Have you received treatment(s) for the urine leakage? If yes, what type of treatment(s)? _____

YES NO Was(were) the treatment(s) effective?

YES NO 65. Do you limit activities because of urine leakage?

If yes, circle the LETTER(s) indicating the activities you that limit below:

- (a) Visiting Friends (d) Sexual Activity (g) Playing cards (j) Relationship with wife/husband/significant other
-
- (b) Visiting Relatives (e) Taking a car trip (h) Shopping (k) Taking vacation
-
- (c) Going to church (f) Exercising (i) Walking (l) Working at a job (m) Other: _____

YES NO 66. Has your urine leakage affected the quality of your life?

If yes, how much? (Circle your answer)

- (a) a little (b) a moderate amount (c) quite a lot

If you would like to include additional comments, use additional paper and return it with this survey form.

This concludes the survey. Thank you very much for participating. Return completed questionnaire by January 1, 1994 to:

Vicki Johnson, R.N., M.S.N.
TTUHSC School of Nursing
3601 4th Street (2C141)
Lubbock, Texas 79430If you would be interested in participating in future studies, send your name, address, and phone number on a separate piece of paper. If you have questions/concerns, you can call the investigator at this telephone number: (806) 743-2730 or 795-3643.**THIS FORM MAY BE PHOTOCOPIED
RETURN SURVEY BY JANUARY 1, 1994**

(Adapted from: Questionnaire for Community Elders - Sue Sherman, R.N., C., M.S.N. - Copyright 1993)

Publications

Handicapped in Walt Disney World is a travel guide book like others and *anyone can use it*. However, it differs because the author precisely describes the accessibility of the attractions, transportation, and loading. The author is disabled and uses a wheelchair for mobility.

It contains 302 pages of detailed information. The author devotes the first one-third of his book to planning a trip, examining transportation options, including air travel, automobiles, vans, recreational vehicles, trains and buses, and providing in-depth information about accessible lodging, shopping, and dining in and around Walt Disney World.

Peter Smith defines people's disabilities in terms of their mobility — some people have difficulty walking, use rental wheelchairs, and have the least difficulty with access; many like himself have their own wheelchairs but routinely transfer, and most of the attractions are accessible to people able to make a similar transfer. A significant number of disabled people using wheelchairs cannot make a transfer, and the book tells how they can also enjoy their visit.

Handicapped in Walt Disney World (ISBN 1-88191-49-X) is available from bookstores, or from the publisher, SouthPark Publishing Group, Inc., for \$10.95 plus \$3.00 shipping and handling, Suite 156-359, 4041 W. Wheatland Road, Dallas, TX 75237 USA (800/669-5657 or FAX 214/296-486).

For a sample copy of **Tide's Inn**, a quarterly newsletter dedicated to the development and expansion of travel by people with disabilities, send a business sized SASE to Travel Industry and Disabled Exchange (TIDE), 5435 Donna Ave., Tarzana, CA 91356 USA.

For a copy of **New Horizons for the Air Traveler with a Disability**, contact Department of Transportation, Office of Consumer Affairs, 400 7th St., S.W., Washington, DC 20590 USA (202/366-2220).

The Travelin' Talk Directory is now available from Travelin' Talk, P.O. Box 3534, Clarksville, TN 37043-3534 (615/552-6670) for \$35.00 in US funds, postage paid. The resource is an 8-1/2 X 11 directory of nearly 550 pages, in six sections, including members of the network, travel and tour agencies, hotels, etc.

The Neuromuscular Disorder Directory, compiled by James and Linda Dobson of the Society for Muscular Dystrophy Information International, is a 40-page guide to finding the world's national or international organizations or support groups concerned with one or more neuromuscular disease. Please make out check or money order (\$8, surface mail; \$10, airmail) in USA, Canadian, or British funds to S.M.D.I. International, and mail to Neuromuscular Disorder Directory, S.M.D.I. International, P.O. Box 479, Bridgewater, Nova Scotia, B4B 2X6 Canada.

The second edition of Spinal Network's **The Total Wheelchair Book** (ISBN 0-943489-03-2), is now available for \$37.95. Add \$5.00 for shipping and handling; add \$2.00 for lay-flat binding. Call 800/338-5412 or 303/449-5412 to order.

June Kailes and Darrell Jones have written a comprehensive manual that details **how to make meetings of all sizes fully accessible**. To order a copy, send \$25.00 to Independent Living Research Utilization (ILRU), 2323 S. Shepherd, Suite 1000, Houston, TX 77019 (713/520-0232, 520-5136 TDD). Bulk rates available.

Continued on page 12



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FAX: 813/623-6935

The month your subscription is due
is above your name on the label.

Renewal notices are sent to
serve as a reminder.

Publications Continued from page 11

The second edition of **Disability Workbook for Social Security Applicants** (ISBN 1-878140-01-9) by Douglas M. Smith, Attorney at Law, was published February, 1993, and is available for \$18.95. For more information, contact Physicians' Disability Services, Inc., P.O. Box 827, Arnold, MD 21012 USA (410/974-1111).

The International Bible Society has published the **New International Version New Testament and Psalms** for the physically disabled for \$11.25 plus \$2.50 S&H. It is in large, 13-point type with special binding and specially coated paper. Contact International Bible Society, P.O. Box 35700, Colorado Springs, CO 80935-3570 (719/488-9200). To order by credit card, call 800/524-1588.

SVETOBENZNIKEM SE SADISTKOU, in Czech only, is an autobiography by Ala Wokoun, who as a young man wanted to travel the world which opened after World War II. But in 1954, he was paralyzed by polio at age 19. Ala accompanies his narrative with a fictitious and quarrelsome dialogue with polio to expose the problems of a polio survivor. Some of the 51 short chapters of the paperback explore the history of the medical struggle against polio, and the development of its treatment. The book is not a medical prescription. Ala's remedy is his elan and humor. For more information contact: Ala Wokoun, Chaberovicka 1333, 182 00 Prague 8, Czech Republic.

What's Wrong With Me, Doc? by E. Michael Gutman, M.D., Diplomate American Board of Psychiatry and Neurology, was written in 1980 because people asked, "Do you have a book that teaches your style of therapy and advice?" The book contains 53 head tips on how to lead a better life and is available from E. Michael Gutman, M.D., 2501 N. Orange Ave., S-414, Orlando, FL 32804-4651 USA for \$11 post-paid.

To receive free pamphlets about medical rehabilitation call 800-GET-REHAB between 8:00 A.M. and 8:00 P.M., EDT, Monday through Friday.

The Arthritis Foundation has a free booklet, entitled **Fibromyalgia** available by contacting your local chapter or calling the toll-free Arthritis Foundation Information Line at 800/283-7800 (Monday-Friday, 9 a.m. to 7 p.m. Eastern time). Fibromyalgia is a condition of very specific signs and symptoms — not a catchall name for any unexplained pain or fatigue. To meet the diagnostic criteria for fibromyalgia,

a person must have widespread pain in all four quadrants of the body that has lasted for at least three months, and tenderness in at least 11 of 18 specified "tender points."

For **National Disability Employment Awareness Month**, the President's Committee on Employment of People with Disabilities prepared an excellent folder of facts and resources. To receive a copy contact: Dina Dorich at 202/376-6200.

World AIDS Day is December 1, 1993. For an Action Kit, contact American Association for World Health, 1129 20th St., NW, Suite 400, Washington, DC 20036 (202/466-5883).

To receive **The Secret of Good Posture**, send a self-addressed stamped envelope to American Physical Therapy Association, 1111 North Fairfax St., Alexandria, VA 22314 USA. ■

Reminders

The Advisory Committee on Immunization Practices recommends vaccination against influenza for persons aged 65 years or older; persons who reside in nursing homes, or other chronic care facilities; chronic cardiovascular or pulmonary disorders, including children with asthma.

International Polio Network will be updating its **Post-Polio Directory** shortly after the holidays. Those currently listed will receive a confirmation letter, which needs to be returned to be included in the **1994 Directory**. Please check the information upon receipt and return it immediately. To be added, please send name, address, and telephone number to International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110-1406.

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Please help us by including your zip code plus four when you are renewing.

Please send both your old and new addresses to: International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110-1406 USA ... when you move, **Polio Network News** will not be forwarded by your post office.