

ANESTHESIA CONCERNS FOR THE POLIO SURVIVOR

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There are three types of anesthesia: general, regional, and monitored anesthesia care (MAC). *General anesthesia* is used primarily for major operations, and the patient is completely asleep. Gas and injected drugs, including muscle relaxants, are usually administered, and a breathing tube is usually placed. With *regional anesthesia*, only part of the body is numb. It is common to give some sedation also, so patients do not remember being awake. Spinal anesthesia and epidural anesthesia are common types of regional anesthesia and anesthetize the lower part of the body only. Regional anesthesia is useful when surgery is limited. It is also commonly used for prostate surgery. This anesthesia uses only a few drugs and is not as complicated as general anesthesia. MAC means that the surgeon injects local anesthesia at the site of surgery while an anesthesiologist gives sedation intravenously and ensures patient safety and comfort during the surgery. Cataract surgery is generally performed with MAC.

Although we know anesthesia today is extremely safe, no one has studied how well post-polio patients do during anesthesia. Patient safety during anesthesia depends on the anesthesiologist knowing the patient's history and selecting an appropriate anesthesia plan, taking into account all of the patient's disorders, as well as the planned surgery. It is vital that polio survivors speak with the anesthesiologist ahead of time and during the pre-surgery interview inform the anesthesiologist of their special conditions such as ventilator use, sleep apnea, body positioning problems, etc. Once the anesthesiologist has the necessary information, a suitable, safe anesthetic can be chosen. With this communication, polio survivors should not fear anesthesia and surgery, but obviously it helps if the anesthesiologist has had experience with polio survivors.

Problems may occur in post-polio patients during anesthesia. Sleep apnea may be worse immediately after surgery. Those individuals who do not have normal stomach emptying may be at risk for vomiting as anesthesia begins. Low blood pressure may occur with normal doses of common anesthesia medications. Changes in all patients' lungs occur during general anesthesia, and lung function is worse in everyone for about 48

hours after surgery. How much trouble polio survivors may face depends on their pulmonary function before the surgery, and they may have an increased need for ventilation post-operatively.

The most likely anesthesia risks for polio survivors occur with general anesthesia. Because they have lost motor nerves, polio survivors are very sensitive to muscle relaxants, and in essence, they may overdose on what may be a usual dose for others. Another significant risk is worsening ventilation after surgery for those with respiratory muscle involvement. This is temporary and is due to changes in the lung with anesthesia.

Measuring response to muscle relaxants is usually done routinely with a nerve stimulator which allows the anesthesiologist to check each person's response to muscle relaxants. With cautious use of muscle relaxant drugs, usually at half the normal dose, and careful monitoring, polio survivors should have no problems. The only study of post-polio patients undergoing anesthesia with the older muscle relaxants found that polio survivors were twice as sensitive to muscle relaxants as the general population. The recommendation was to cut the dose in half. Clinically, I think that recommendation is appropriate. If a patient also had vomiting pre-operatively and had abnormal electrolytes (salts in the blood), even less than half the usual dose might be needed. Low electrolytes, common after vomiting and diarrhea, make muscle relaxants last longer.

"Once the anesthesiologist has the necessary information, a suitable, safe anesthetic can be chosen. With this communication, polio survivors should not fear anesthesia and surgery ..."

With muscle relaxant drugs, all muscles are paralyzed but to varying degrees. The sensitivity of various muscles depends on muscle size and some other factors we don't entirely understand. In general, the eye muscles are very sensitive to muscle relaxants while breathing muscles are very insensitive to muscle relaxants — they are the last to be paralyzed when muscle relaxants are administered.

The paralyzing action of all muscle relaxant drugs eventually ends. The drugs are either redistributed away from the nerves, and thus diluted, excreted by the kidneys, or broken down by blood or liver enzymes. If paralysis is prolonged, the anesthesiologist would use a ventilator to breathe for the patient until the patient could breathe on his/her own, perhaps for as long as an hour, or more. Use of a ventilator is fairly common after major surgery and is not considered a serious complication.

Curare was the first available muscle relaxant drug. It comes from natural plants and has many possible side effects, such as flushing of the skin and lowering of blood pressure. When it was first introduced, we also did not have any medicine to reverse its effects. From the time curare was introduced in the late 1950s, drug companies were always actively trying to synthesize better muscle relaxants. They have been successful in the last few years. As a plant preparation from the Amazon, curare is also difficult to obtain now. It is not commonly used today, because there are so many better synthetic muscle relaxant drugs.

Common muscle relaxant drugs are vecuronium, pancuronium, mivcurium, rocuronium, atracurium, cis-atracurium, and succinylcholine. There are theoretical reasons to prefer mivcurium, atracurium, and cis-atracurium over the other drugs. The action of these drugs ends by an enzymatic breakdown and is not dependent of redistribution of the drug away from the nerves. There is no information on these drugs with post-polio patients, but theoretically, there would be less chance for overdose. If overdose did occur, the effects would not last as long.

SELMA HARRISON CALMES, MD, Chair, Department of Anesthesiology, Olive View-UCLA Medical Center, contracted polio at age 8 in Southern California. She graduated from Baylor Medical School in Houston in 1965 (one of three women in a class of 1984).

Short-acting muscle relaxants often used in anesthesia are rocuronium and succinylcholine. They cause muscles to contract first, before paralysis occurs, and are often used at the start of general anesthesia to help place a breathing tube. [A new airway device, the laryngeal mask airway (LMA), helps support an adequate airway instead of a breathing tube, and muscle relaxants are not required to place it. However, patients can aspirate stomach contents into the lungs with the LMA. In my experience, many post-polio patients are at risk for aspiration because they often have gastroesophageal reflux or a hiatal hernia, and the LMA would not be safe for them. A breathing tube prevents aspiration which can be a serious and even fatal complication.] Succinylcholine and rocuronium can cause severe muscle pain in polio survivors especially if the survivors will be up and about soon after surgery and should be avoided if possible.

Because of the hazards of general anesthesia in post-polio patients, it is useful to consider regional or MAC instead, if the operation can be done with those anesthetics. There is much less assault on the body and far fewer drugs are used. An epidural anesthetic probably has less risk for aggravating any pre-existing nerve damage in polio survivors and would be a good alternative to a spinal or general anesthetic. Polio survivors, as with the general population, should be in the best shape possible for elective surgery. They should not have a cold or bronchitis. If they still smoke, they should stop smoking as soon as they know about the surgery. They should control their weight and eat a high-protein diet after surgery to help their muscles stay in the best condition possible.

If you are about to undergo surgery, you must inform the anesthesiologist about your post-polio problems, possible sensitivity to muscle relaxants, and the need to monitor your response to them. If you are having elective surgery and have not had a chance to speak with the anesthesiologist beforehand, surgery should be postponed until this critical conversation occurs. Many anesthesiologists now have clinics or offices where they see patients several days before surgery. If the surgery is an emergency and you are physically able to communicate with the anesthesiologist, please do so before the surgery, or have a family member who is knowledgeable about your special conditions speak for you. If you are not satisfied with the response of the anesthesiologist, ask for another. With attention to all these details, you can have surgery safely and remain in the best possible health. ◀

UPDATE ON QUALITY OF LIFE PROJECT

Spring 1995 *Polio Network News* (Vol. 11, No. 2) featured a request from Nancy Seyden at the Research and Training Center on Neuromuscular Diseases, University of California-Davis, for volunteers to complete a survey for their Quality of Life Project.

During the past year, Seyden and Ted Abresch surveyed 620 adults (368 from *Polio Network News*) to identify variables that affect quality of life and community integration of individuals with neuromuscular disabilities. They are still collecting more surveys and will produce a much more comprehensive report when all the data has been accumulated, but can offer some preliminary information.

☼ Participants had major difficulties finding disability-related information and obtaining services that would help them with their disability and healthcare. Fifty-seven percent of individuals surveyed reported that it was somewhat hard to almost impossible to get the information and services they need. The ability to obtain information and services has not significantly improved over the past ten years (as compared to a Lou Harris & Associates survey that was conducted in 1986).

☼ Participants identified the following areas in which they need information: medical research, disability rights and legal program, advocacy, computer technology, diet and nutrition, and durable medical equipment. Over 60% of the participants need or urgently need information about medical research that may affect their disease. Thirty-seven percent of individuals surveyed need more information about durable medical equipment.

☼ Primary impairments were identified as muscle weakness (88% of those surveyed), fatigue (75%), pain (58%), difficulty sleeping (42%), difficulty breathing (23%). Secondary effects as a result of these impairments is the ability to exercise and control weight.

☼ Pain is a major factor in individuals with neuromuscular disease and it significantly reduces life satisfaction. Fifty-eight percent of those surveyed reported moderate pain in the four weeks prior to the survey and 21% reported that their pain was severe or very severe. This pain moderately or severely interfered with normal work activities in 52% of those surveyed.

☼ The areas of research that would most improve their quality of life were directly related to the impairments cited and information needs. Participants would like to see more research in the following areas: fatigue, effect of exercise, muscle weakness, pain, teaching

health professionals about neuromuscular diseases, better and more affordable assistive devices, and durable medical equipment.

☼ Seventy-seven percent of post-polio individuals surveyed were very satisfied with their lives in general. Factors associated with higher life satisfaction were: perceived control over one's activities, better self-assessed health status (regardless of degree of disability), minimization of problems, better education, and spiritual faith. Factors that did not correlate with life satisfaction were self-reported disability and income level.

THE RESEARCH AND TRAINING CENTER ON NEUROMUSCULAR DISEASES is funded by a grant from the National Institute on Disability and Rehabilitation Research.

POST POLIO RESEARCH

The Effect of Recombinant Insulin-like Growth Factor 1 (rhIGF-1) Upon Exercise-induced Fatigue and Recovery in Patients with Post Polio Syndrome

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Objective To evaluate the safety, tolerability, and efficacy of subcutaneous administration of rhIGF-1 in patients with post polio syndrome (PPS).

Background Fatigue is a major complaint for patients with PPS. Patients have excessive muscular fatigability and delayed recovery after fatiguing exercise. rhIGF-1 increases muscle mass, sprouting and neuronal survival in experimental models, slows the decline of function in patients with ALS, and might reduce fatigue in PPS.

Design/Methods 22 patients with PPS were randomized to receive .05 mg/kg rhIGF-1 or placebo subcutaneously b.i.d. for 3 months. The randomization was 3:1 for drug vs. placebo. The primary endpoints were the decline in maximum voluntary contraction (MVC) during a standardized fatiguing protocol and the degree of subsequent recovery within 15 minutes in treated vs. placebo patients. Secondary endpoints included changes in muscle strength, metabolism as

CONTINUED ON PAGE 4

measured by MR spectroscopy (MRS), muscle biopsy (quantitative morphometric analysis), the Sickness Impact Profile and various rating scales of fatigue.

Results At the end of three months there was no change comparing treated (decline of MVC to $66.2 \pm 28.19\%$ at baseline vs. $59.6 \pm 25.7\%$ after 3 mos) and placebo (decline of MVC to $60.0 \pm 22.8\%$ at baseline vs. $60.8 \pm 22.3\%$ after 3 mos, $p=0.78$) patients in the degree of muscular fatigability or muscle metabolism by MRS. There was, however, a statistically significant increase in the degree of recovery of force (MVC) within 15 minutes after fatiguing exercise in patients treated with rhIGF-1 ($-1.58 \pm 13.6\%$ at baseline vs. $+12.9 \pm 9.2\%$ after 3 mos, $p=0.001$) compared with placebo ($+2.9 \pm 13.6\%$ baseline vs. $-2.8 \pm 18.4\%$ after 3 mos, $p=0.28$) ($p=0.007$ adjusted difference between treatments). No significant differences were found in terms of muscle strength, morphometric analysis of muscle biopsies (fiber type composition, fiber size, N-CAM positive fibers), in either fatigue or functional assessment scales or in the Sickness Impact Profile. Side effects of rhIGF-1 were time limited and the drug was generally well tolerated.

Conclusion Subcutaneous rhIGF-1 enhanced recovery after fatiguing exercise in patients with rhIGF-1, but did not alleviate excessive exercise-induced fatigability in patients with post polio syndrome.

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LEAD INVESTIGATOR, ROBERT G. MILLER, CHAIRMAN, DEPARTMENT OF NEUROLOGY, CALIFORNIA PACIFIC MEDICAL CENTER, SAN FRANCISCO, CA, OFFERS HIS COMMENTS:

Since fatigue is a major problem in PPS and since IGF-1 nourishes motor neurons, we undertook a study to evaluate the effect of IGF-1 on fatigue in patients with PPS.

We and others have found in previous studies of PPS that a standardized period of fatiguing exercise produces both greater fatigue and delayed recovery in persons with PPS. We identified 20 persons with PPS who were randomly assigned to receive placebo or IGF-1 subcutaneously for three months. The fatiguing exercise and recovery were evaluated both before and again after three months of injections. Both the amount of fatigue and the degree of recovery were the two major outcome measures of this study. No effect of IGF-1 was found upon the fatigue of persons with PPS in this study, although there was more variability of the results than we had seen in our previous study, so this point deserves further study. However, there was improved recovery that was statistically significant for those who

received IGF-1. We are not sure how clinically meaningful this would be nor do we understand the mechanism of this finding. But we are encouraged that this model might be useful and also that further study of IGF-1 in PPS should be undertaken.

Editor's Note: rhIGF-1 is an experimental drug and has not yet been approved by the Food and Drug Administration.

GERMAN POST-POLIO BOOK PUBLISHED

Poliomyelitis und ihre späten Folgen: PPS — Die zweite Herausforderung (Poliomyelitis and Its Late Effects: PPS — The Second Challenge), written by Gertrud Weiss, is a concise, comprehensive, 122-page book (ISSN 0941-603X; ISBN 3-9804519-1-7) which explains the late effects of polio to physicians and polio survivors using supporting medical literature and life examples.

The book, in German only, was published and is distributed by Bundesverband Polio e. V., Thaestr. 27, D-35392, Giessen, Germany for DM 16.90.

Gertrud Weiss, who contracted polio in 1928 at the age of eight, studied metallurgy and worked from 1943 to the end of the war in an industrial laboratory. In 1947, she joined an international editorial staff in Munich and in 1952 became a science writer for the United States Information Service where her reports were widely reprinted by German, Swiss, and German language journals and newspapers. Having covered many different topics on science, medicine, and technology, she focused on polio and post-polio syndrome after participating in G.I.N.I.'s 1983 international post-polio and independent living conference. ←

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HINTS ON CONSERVING ENERGY

GRACE R. YOUNG, MA, OTR, FRESNO, CALIFORNIA

As a polio survivor, I have had to modify many areas of my life over the years. I assure you, however, that this modifying is not as oppressive as it may sound. By conserving energy in less important areas, I can still do the activities that I enjoy — that's what energy conservation is all about. Here are a few ideas I hope you will find helpful.

Rest before you become aware of fatigue, a difficult task because most of us were taught to ignore pain and fatigue. Before starting an activity, decide how long you will work and when you will take rest breaks. For stressful projects, set a timer and break the activity into segments of half-hour work and fifteen minutes rest. Lie down during your rest break — listen to music or watch television, meditate, visualize or read, but get off your feet.

Don't become over-ambitious on days when you feel good, or you may then be sidelined for several days. Alternate light and heavy chores throughout the week. Don't do anything heavy if you're planning an evening activity.

Sit whenever possible — for showering, dressing, grooming, working with hobbies, preparing meals, etc. Sitting takes 25% less energy than standing. When you sit, make sure that your work heights are about an inch below elbow level. A drafting chair on casters with a pneumatic seat lift works well, but back it into a corner before hoisting yourself onto the raised seat or the chair may roll out from under you. Other ways to obtain a lower work surface: use a beanbag lapboard, a wooden cutting board on your lap, or an adjustable-height, hospital bedside table, which you may find in a thrift store.

Organize your home so that items are easy to reach and you don't have to duplicate motions. In the kitchen, store frequently used items at a height between your hips and your lips. Use vinyl-coated wire racks to store dishes in stacks of their own kind; store pots and skillets individually on wire racks so that you don't have to lift top items to get to one on the bottom. Use stacking storage bins on wheels and wire shelf units that hook over pantry doors. One- and two-level sliding racks, bins, baskets, and shelf trays can make base cabinets for food staples and cleaning supplies.

GRACE R. YOUNG, MA, OTR, is an occupational therapist and a polio survivor who has published and lectured extensively on energy conservation for polio survivors. She recently retired from Kaiser-Permanente in Downey, California and is presently working at San Joaquin Valley Rehabilitation Center in Fresno, California.

Don't put away items you use frequently. After washing pans or skillets, for example, let them dry on top of the stove. Let dishes dry in a rack and then use them in setting the table for the next meal.

Arrange your home to minimize trips. Install floor-to-ceiling pole shelves over the toilet tank in each bathroom for storing towels and washcloths. Store sheets and pillowcases in each bedroom where they are used.

Duplicate supplies used in different areas. For example, store cleanser and sponges under each sink and keep a broom and dustpan in several locations.

Avoid buying deep pile carpets with thick padding. Wheelchair users find plush carpeting difficult to maneuver on, and people with walking problems may have difficulty maintaining their balance on it. Throw away throw rugs that can slip, and remember that ceramic tile floors are slippery when wet.

And, finally, use mechanical help for carrying things. Carrying heavy items changes your center of gravity and stresses your trunk, arm, and leg muscles. A kitchen utility cart on casters, available in most housewares departments, allows you to transport dishes, glasses, silverware, and food from the counter to the table and back again in one trip. Use the cart to carry laundry and cleaning items, and push it along when you straighten the house. A lightweight luggage cart is useful in many situations. Use one to carry purchases, to transport articles between the car, house, or office, and to move articles from room to room. I keep a luggage cart open and ready to use whenever I have to carry heavy or bulky items around the house. (The definition of "heavy," of course, depends upon the strength of the individual.)

You undoubtedly have many other ideas that are appropriate to your particular lifestyle. Look upon energy conservation as just the latest challenge in your life. ↵

WHAT IS OCCUPATIONAL THERAPY?

Occupational therapy is a health and rehabilitation profession.

Occupational therapy is skilled treatment that helps individuals achieve independence. Services include:

- ◆ Customized treatment programs aimed at improving abilities to carry out activities of daily living
- ◆ Comprehensive evaluation of home and job environments and recommendations on necessary adaptation
- ◆ Assessments and treatment for work performance skills
- ◆ Recommendations and training in the use of adaptive equipment to replace lost function
- ◆ Instructions to family members and attendants in safe and effective methods of caring for individuals

Extracted from materials of the American Occupational Therapy Association, Inc., 4720 Montgomery Lane, P.O. Box 31220, Bethesda, Maryland 20824-1220, 301/652-AOTA (2682), 301/652-7711 FAX, or 800/377-8555 TDD.

Universal Design Features in Housing for ...

... Entrances

- Accessible route from vehicle drop off or parking
- Maximum slope of 1:20 to entry door
- Covered entryway
- 5x5-foot minimum maneuvering space
- Package shelf or bench to hold parcels, groceries, etc.
- Full length sidelight at entry door
- Movement sensor light controls
- Ambient and focused lighting (at keyhole)
- High visibility address numbers

... General Interior

- 5 lb. maximum force to open doors
- 32-inch minimum clear door opening width
- 18-inch minimum space at latchside of door
- Flush threshold (maximum of 1/2-inch rise)
- Lever door handles
- Adjustable height closet rods and shelves
- Accessible route (42-inch minimum) throughout
- Light switches at 44/48-inch maximum height
- Electrical receptacles at 18-inch maximum height
- View windows at 36-inch maximum sill height
- Crank-operated (casement) windows
- Loop handle pulls on drawers and cabinets
- High contrast, glare-free floor surfaces and trim
- 5x5-foot maneuvering space in all rooms

... Bathrooms

- Toilet centered 18 inches from side wall
- 30x48-inch area of approach in front of all fixtures
- Grab bar blocking in walls around toilet
- Grab bars in tub or shower
- 32-inch minimum lavatory counter height
- Knee space under lavatory
- Lever-type faucets
- Mirror to backsplash at lavatory
- 18-inch maneuvering space at both ends of tub or shower
- Offset controls in tub or shower
- Integral transfer seat in tub or shower
- Adjustable height shower head
- Mixer valve with pressure balancing and hot water limiter

... Kitchens

- Knee space under sink and near cooktop
- Lever-type faucets
- Variable height work surfaces
- Contrasting border treatment on countertops
- Stretches of continuous counter for sliding heavy objects
- Full-extension pull-out drawers
- Pull-out shelves in base cabinets
- Adjustable height shelves in wall cabinets
- Full height pantry cabinets for up and down storage
- 30x48-inch area of approach in front of all appliances
- Front-mounted controls on appliances
- Cooktops with staggered burners to eliminate dangerous reaching
- Glare-free task lighting

The Center for Universal Design is a national research, information, and technical assistance center that evaluates, develops, and promotes accessible and universal design in buildings and related products. The Center's work reflects the belief that all new buildings and products, to the greatest extent possible, should be usable by everyone regardless of their level of ability or disability. Contact the Center for Universal Design for listings of their useful and reasonably priced publications.

The Center for Universal Design
North Carolina University, Box 8613, Raleigh, NC 27695
919/515-3082 V/TTY; 919/515-3023 FAX; 800/647-6777;
e-mail: cahd@ncsu.edu
[http:// www2.edu./ncsu/design/cud](http://www2.edu./ncsu/design/cud)

ADDITIONAL RESOURCES

Residential Remodeling and Universal Design: Making Homes More Comfortable and Accessible, from HUD's Office of Policy Development and Research, provides technical guidance on selecting and installing universal features during home remodeling or renovation.

The guidebook is organized by design areas, with illustrations highlighting common barriers in the home and universal features that can be used to remedy them. It is a handy resource for the housing professional and the do-it-yourselfer alike. To order, request *Residential Remodeling and Universal Design: Making Homes More Comfortable and Accessible* (ACCN-HUD-7197). Mail \$5.00 for each copy to HUD USER, P.O. Box 6091, Rockville, Maryland 20849. All orders must be prepaid. To place credit card orders or for more information, call 800/245-2691; 800/483-2209 TDD; 301/251-5767 FAX.

For one free copy of *Making Your Home Accessible: Assessing Your Modification Needs*, contact Paralyzed Veterans of America, 801 Eighteenth Street, NW, Washington, DC 20006-3715, 202/USA-1300; 202/416-7622 TDD; 202/785-4452 FAX. ←

STATE ASSISTIVE TECHNOLOGY PROJECTS

The Technology Related Assistance for Individuals with Disabilities Act of 1988 (amended in 1994)

supports consumer-driven statewide technology-related projects for individuals with disabilities of all ages. The same act defines an assistive technology device as, "any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities." Examples include wheelchairs, ventilators, canes, magnifying glasses, one-handed can openers, etc.

An assistive technology service is defined as "any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device." Examples include the services provided by the occupational, physical, and speech therapies.

State Projects The focus and the quality of service varies for each program listed below. Many work on changing policies at the state level such as writing lemon laws or eliminating sales tax for durable medical equipment and monitoring proposed health insurance bills. Many are a good source for information on available assistive technology and can provide specific information to individuals. The projects do not provide funding for equipment, but some have equipment exchange programs and can provide leads to funding.

The 800 numbers listed below are for instate only.

ALABAMA Statewide Technology Access and Response Project (STAR) System for Alabamians with Disabilities
800/STAR-656

Assistive Technologies of ALASKA
800/770-0138 Voice/TDD

AMERICAN SAMOA Assistive Technology Project
684/699-1529
684/233-7874 TDD

ARIZONA Technology Access Program (AZTAP)
800/477-9921
520/324-3177 TDD

ARKANSAS Increasing Capabilities Access Network
800/828-2799
501/666-8868 TDD

CALIFORNIA Assistive Technology System
800/390-2699
916/324-3062 TDD

COLORADO Assistive Technology Project
800/255-3477
303/534-1063 TTY

CONNECTICUT Assistive Technology Project
800/537-2549
860/298-2018 TDD

DELAWARE Assistive Technology Initiative (DATI)
302/651-6790
302/651-6794 TDD

D.C. Partnership for Assistive Technology (DCPAT)
202/546-9163
202/546-9168 TDD

FLORIDA Alliance for Assistive Service and Technology (FAAST)
800/322-7881
904/487-3278 TDD

Tools for Life GEORGIA
800/497-8665
404/657-3085 TDD

GUAM System for Assistive Technology (GSAT)
671/734-9309

HAWAII Assistive Technology Training and Service Project (HATTS)
808/532-7110 Voice/TDD

IDAHO Assistive Technology Project
800/432-8324
208/885-3559 TDD

ILLINOIS Assistive Technology Project
800/852-5110
217/522-9966 TDD

INDIANA ATTAIN (Accessing Technology through Awareness in Indiana) Project
800/545-7763
800/743-3333 TDD

IOWA Program for Assistive Technology
800/331-3027 Voice/TDD

Assistive Technology for KANSANS Project
800/KAN-DO IT
316/421-0954 FAX/TDD

KENTUCKY Assistive Technology Services Network (KATS)
502/564-2733
800/327-5287

LOUISIANA Assistive Technology Access Network (LATAN)
800/270-6185

CONTINUED ON PAGE 8

MAINE Consumer Information and Technology
Training Exchange (Maine CITE)
207/621-3195 Voice/TDD

MARYLAND Technology Assistance Program
800/TECH-TAP
410/333-4975 TDD

MASSACHUSETTS Assistive Technology Partnership
(MATP Center)
800/848-8867

MICHIGAN TECH 2000
517/373-4058
517/373-4035 TT

MINNESOTA STAR Program
800/657-3862
800/656-3895 TT

MISSISSIPPI Project START
800/852-8328 Voice/TDD

MISSOURI Assistive Technology Project (MATP)
800/647-8557 Voice/TDD

MONTECH (MONTANA)
800/732-0323

NEBRASKA Assistive Technology Project
800/742-7594

NEVADA Assistive Technology Collaborative
800/992-0900
702/687-3388 TDD

NEW HAMPSHIRE Technology Partnership Project
603/224-0630

NEW JERSEY Technology Assistive Resource Program
800/342-5832
800/382-7765 TDD

NEW MEXICO Technology Assistance Program
(NMTAP)
800/866-ABLE

NEW YORK State TRAITD Project
800/522-4369
518/473-4231 TTY

NORTH CAROLINA Assistive Technology Project
800/852-0042

NORTH DAKOTA Interagency Program for
Assistive Technology (IPAT)
800/451-8693
701/265-4807 TDD

Commonwealth of the Northern MARIANA ISLANDS
Assistive Technology Project
670/322-3015 Voice/TDD

OHIO TRAIN
800/784-3425
614/292-3162 TDD

OKLAHOMA ABLE TECH
800/257-1705

OREGON Technology Access for Life Needs
Project (TALN)
800/677-7512
503/361-1201 TDD

PENNSYLVANIA's Initiative on Assistive Technology
800/204-PIAT
800/750-PIAT TT

PUERTO RICO Assistive Technology Project
800/981-6033
809/754-8034 TDD

RHODE ISLAND Assistive Technology Access
Project (ATAP)
800/916-TECH
401/421-7016 TDD

SOUTH CAROLINA Assistive Technology Program
800/922-1107
803/822-5404 TDD

DakotaLINK (SOUTH DAKOTA)
800/645-0673 Voice/TDD

TENNESSEE Technology Access Project
800/732-5059

TEXAS Assistive Technology Partnership
800/828-7839 Voice/TT

U.S. VIRGIN ISLAND Technology-Related Assistance
for Individuals with Disabilities (TRAID)
809/693-1323

UTAH Assistive Technology Program
800/333-UTAH

VERMONT Assistive Technology Project
800/639-1522 Voice/TDD

VIRGINIA Assistive Technology System
800/435-8490

WASHINGTON Assistive Technology Alliance
360/438-8000
360/438-8644 TDD

WEST VIRGINIA Assistive Technology System
(WVATS)
800/841-8436

WISTECH (WISCONSIN)
800/426-STEP
608/243-5601 TDD

WYOMING's New Options In Technology (WYNOT)
307/777-4386 Voice/TDD

Readers Write

"This should be easy: I have a bad tooth, lower jaw farthest back, that needs to be extracted. The problem is that I'm missing many upper-body muscles. My neck, jaw, and shoulders are very weak. They function minimally only because Jacquelin Perry MD, Rancho Los Amigos Medical Center, Downey, California, helped me to get the top ten vertebrae of my spine fused a few years ago. I must sit upright to keep everything together. No dentist can yank my tooth out without taking my jaw with it. Last year, I had the second tooth back cut out successfully, with my mouth shut and my chin resting on my "chin crutch" to keep my air passage open, while the dentist stretched the side of my mouth back and cut in from the outside of my gum. Worked beautifully, too.

"Now my dentist says this tooth is so far back that he's afraid he'll lose part of it down my air passage. He wants me to go into the hospital and have it removed under general anesthesia. My primary care physician does not believe that this method is safe because of the condition of my neck. In addition, I have experienced marked weakness in my throat in the past, which I attribute to the local dental anesthesia. My throat feels less weak after a week or two, but I always feel as if I lost a little muscle strength during the dental process, and I have so little to lose.

"Has anyone else experienced similar problems? Did you find a solution? I'd love to hear what you have to say."

Nancy Carter,
7304 S. 140th Ave.,
Omaha, Nebraska 68138
e-mail: n.carter@worldnet.att.net

"I had bulbar and spinal polio in 1948 when I was four months old. My spine was fused at age 8. My neck is extremely weak and does not tolerate even slight jerks, so I wear a cervical collar and when sitting, use head support.

My 'roving throne' (PaceSaver Plus three-wheeler) is over ten years old, but coasts beautifully to a smooth stop. Shopping for a new three-wheeler or power chair has been problematic because the new brake systems automatically lock into place at each stop which causes a slight jerk which my neck cannot tolerate. If you have ideas for a smoother ride or if you have a similar problem (neck weakness), please contact me through G.I.N.I. so that we can benefit from 'neckworking' together."

Becky, Houston, Texas

"I'm post-polio (since 1955) with severe paralysis. I'm a tall person who's most comfortable in a wheelchair with an 18-inch-deep seat. An engineer friend from the University of Missouri created a foot control on a 3P Everest & Jennings wheelchair for me in the early '80s. That model is obsolete now, but the control system works so well for me that I've kept mine in running condition. Unfortunately, metal fatigue is starting to destroy the frame. E&J says it can build a new one, but only by comparing my frame to the old one. (It seems they destroyed all of the blueprints for this model.) I am searching for an old, discarded 3P chair, with the 18-inch-deep seat, so I can either use that frame, or send it to E&J, and will not have to part with my chair for the time it will take for them to build a new one.

"If a reader knows of one, depending on the condition, I would take the whole chair. (You can't have too many spare parts when you're driving an Edsel.) I'll gladly pay for the shipping costs."

Richard L. Wieler,
2401 W. Broadway, #904,
Columbia, Missouri 65203
e-mail: rwieler@mail.coin.missouri.edu

"I have recently discovered that the use of support hosiery helps relieve some of the muscle pains in both legs."

Joe, California

"I recommend *Managing Pain before It Manages You* by Margaret A. Caudill, MD, PhD, a 200+ workbook-style book about what really increases and decreases pain, relaxation techniques, effective communication skills, problem-solving strategies, setting realistic goals, and medications and their effects. It is available for \$18.95 from Guilford Publications, 72 Spring Street, New York, NY 10012 (800/365-7006)."

Dorothy, Maine

"I wear a size 5 left shoe and a size 8 right shoe. I have found that Nordstroms Department stores will sell mismates at the price of one pair of shoes. You must have at least two full sizes difference to qualify."

Linda, Nevada

Editor's Note: In *Rehabilitation Gazette* (Vol. 37, No. 1), we published a request by a polio survivor who wanted to connect with those who have had a hysterectomy. We received numerous offers of assistance which were passed along. She would like to thank all who contacted her and apologize for not getting in touch with everyone. Her surgery was successful and she will share what she learned in a future G.I.N.I. publication.

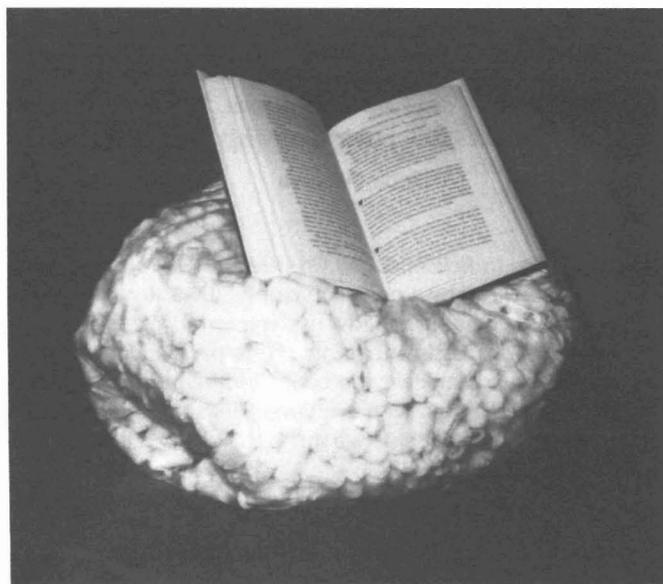
CONTINUED ON PAGE 10

"I have devised a way to add 3 inches to the height of your favorite chair for about \$2.00. It makes a big difference when it comes to getting up out of a chair that is too low. Measure the diagonal distance from the front chair leg to the back chair leg. Cut two pieces of 2x4 to that length. Also cut four separate blocks (about 4-5 inches long) from the remaining 2x4 and then nail on the end of each long piece. Drill a small shallow hole to correspond to the diameter of the glides on the bottom of the chair legs. Reverse the other one to form an X and fasten together with a couple of nails. Rest the chair on top. Hope this helps ... it's helped me.



"I am a potter and sculptor and I have a great deal of trouble with my shoulders so I also have devised a book holder. Fill a plastic (wastebasket size) cleaners bag with packing foam peanuts. Tie top in a knot. It is weightless and will easily conform to your lap and you can prop your book on top at any convenient angle. If you want to get fancy, you can sew a cloth bag and drop the plastic bag inside."

Suzanne, Connecticut



TAKE ADVANTAGE OF COMMUNITY ACCESS

If you're looking for an effective way to spread the word about post-polio to your support group members and your community, check with your cable company or community-access facility.

Why? Community-access television is an important tool for making our free-speech guarantees under the First Amendment a reality in the electronic age. Congress recognized the importance of access television in the Cable Communications Policy Act of 1984, calling it "the video equivalent of the speaker's soapbox" and "the electronic parallel to the printed leaflet."

Today's community-access television operations, which provide training, equipment, and cable-channel time to citizens on a non-discriminatory basis, are based on one of the oldest and most basic human needs: the need to communicate our ideas and achievements to each other - to tell the stories that create and sustain our culture.

Consider the story of Sheila Maxwell, employed by the Easter Seal Society of Oregon to coordinate the post-polio program, who faced the challenge of getting information to polio survivors, their families, and medical professionals. Excellent speakers knowledgeable in post-polio were making presentations to the Portland/Metro support group in its early stages of development, presentations very beneficial to the people who attended the meetings, but they were only a small percentage of the membership.

Following the denial of a grant request for funds to purchase a video camera to be used in videoing the speakers, Sheila met with community development staff members at Tualatin Valley Community Access (TVCA) Beaverton, Oregon who was very supportive of non-profit organizations using its facilities, and assured her that she could produce programs that could be aired on a regular basis.

Sheila attended workshops offered by TVCA and learned, hands-on, how to operate camera, audio, lighting, and editing equipment, how to develop graphics, etc. She received her certification as producer/director in the early part of 1992. Between then and March of 1997, Sheila, with the help of eight certified volunteer crew members, produced about 50 one-hour programs that have aired on television. Topics include the neurological aspects of polio, sleep apnea, bracing, emotional aspects of living with chronic illness, social security disability, and vocational rehabilitation.

In 1995, TVCA awarded Sheila the "Acorn Award" for outstanding achievement in public health education for post-polio survivors and medical professionals. Master broadcast tapes air on local community-access stations from TVCA, which reaches 100,000 households. Tapes

CONTINUED ON PAGE 12



Seventh International Post-Polio & Independent Living Conference

May 29th - 31st, 1997
St. Louis Marriott Pavilion Hotel

AUDIO & VIDEO TAPES ORDER FORM

Check the tapes you wish to purchase.

Tape #1 THE BIG PICTURE audio video

Lessons, Transforming, Target 2000, NHIS
Speakers: Joan L. Headley; Karen Hirsch, PhD;
Robert A. Keegan; Linda Tompkins
Date: 5/29/97 Time: 8:30 am - 10:30 am

Tape #2 THE BIG PICTURE audio video

Motor Neurons, Aging, Wellness
Speakers: Neil Cashman, MD;
Margaret L. Campbell, PhD; Agnes Wallbom, MD
Date: 5/29/97 Time: 10:30 am - noon

Tape #3 HOW WILL I SUPPORT MYSELF? audio video

Employment Decisions
Speakers: Stuart J. Glassman, MD; Linda Baker Oberst;
Linda L. Bieniek
Date: 5/29/97 Time: 2:00 pm - 3:15 pm

Tape #4 HOW WILL I SUPPORT MYSELF? audio video

Social Security, Medicare, Health Insurance
Speakers: Thomas Gloss; James G. Scott; Daniel J. Ashbaker;
Linda L. Bieniek
Date: 5/29/97 Time: 3:45 pm - 5:00 pm

Tape #5 HOW CAN I MAINTAIN WELLNESS? audio video

Team Approach; The Survivor; Primary Care; Specialist
Speakers: Frederick M. Maynard, MD; Ellen Fay Peak;
Marny Eulberg, MD; Martin B. Wice, MD
Date: 5/30/97 Time: 8:30 am - 10:00 am

Tape #6 HOW CAN I MAINTAIN WELLNESS? audio video

Role of Activity; Nutrition; What Works; Clinic Survey
Speakers: James Agre, MD, PhD; Lauro S. Halstead, MD;
Stanley K. Yarnell, MD
Date: 5/30/97 Time: 10:30 am - noon

Tape #7 SESSION I — HOW WILL I GET AROUND? audio video

Change, Bracing, Seating, Shoulders
Speakers: Jacquelin Perry, MD; Mark K. Taylor, CPO;
Robbie B. Leonard, MS, PT; Mary Ann Keenan, MD
Date: 5/30/97 Time: 2:00 pm - 3:15 pm

Tape #8 SESSION I — HOW WILL I CARRY OUT MY DAILY ACTIVITIES? audio video

Polio Rehab, PT, OT, Re-thinking
Speakers: Paul E. Peach, MD; Marianne T. Weiss, LPT;
Beth Kowall, MS, OTR; Nancy Caverly, OTR
Date: 5/30/97 Time: 3:45 pm - 5:00 pm

Tape #9 SESSION II — HOW DO LATE EFFECTS OF POLIO AFFECT THOSE AROUND ME? audio video

Maintaining and Developing Relationships
Speakers: Gail Genereau; Lillian Genskow, RN;
Jack Genskow, PhD, CRC; Margaret E. Backman, PhD
Date: 5/30/97 Time: 2:00 pm - 3:15 pm

Tape #10 SESSION II — HOW DO THE LATE EFFECTS OF POLIO AFFECT THOSE AROUND ME? audio video

Finding Peace, Two-Way Street, True Colors
Speakers: Robert J. Ronald, SJ; Joyce Tepley, LMSW/ACP,
LPC; Kathleen Navarre, PhD; Angela Radlinski
Date: 5/30/97 Time: 3:35 pm - 5:00 pm

Tape #11 SESSION III — FORUM ON HOME MECHANICAL VENTILATION audio video

Danish, Japanese, American Experience
Speakers: Grethe Nyholm, RNP; Kimiyo Satoh;
Yoichi Sakakihara, MD, PhD; Jean Graber;
Edward Oppenheimer, MD
Date: 5/30/97 Time: 2:00 pm - 3:30 pm

Tape #12 SESSION III — FORUM ON HOME MECHANICAL VENTILATION audio video

Effects of Aging on Equipment Choices, Face Masks
Speakers: Augusta Alba, MD; Susan Sortor Leger, RRT
Date: 5/30/97 Time: 3:45 pm - 5:00 pm

Tape #13 SESSION A — POST-POLIO RESEARCH audio video

Speakers: Burk Jubelt, MD; Daria A. Trojan, MD
Date: 5/31/97 Time: 8:30 am - 9:30 am

Tape #14 SESSION C — FATIGUE: MANY CAUSES AND POSSIBLE MANAGEMENT audio video

Speakers: Mavis Matheson, MD; Stanley K. Yarnell, MD
Date: 5/31/97 Time: 9:45 am - 10:45 am

Tape #15 SESSION B — ISOLATING AND MANAGING PAIN audio video

Speakers: Ann E. Hueter, RPT; Paul E. Peach, MD
Date: 5/31/97 Time: 11:00 am - noon

Tape #16 THE PERSONAL AND THE GLOBAL audio video

Speakers: Caroline Heckman; Liliana Bieberach;
Javier Riba; Kimiyo Satoh; Cyndi Jones
Date: 5/31/97 Time: 2:00 pm - 4:00 pm

INFORMATION FOR ORDERING CONFERENCE TAPES

Please indicate which tape you would like by checking the box of each tape title. The cost of each audio tape (1-1/2 hours or less) is \$6 plus 6.475% tax; each video cassette tape is \$13 plus 6.475% tax. Please add \$3.50 for postage and handling. Fill in the address of the person who is to receive the tapes below.

NOTE: Large orders and international orders may require additional shipping cost.

Name _____

Street _____

City _____ State _____

Zip Code _____ Phone _____

Please make check payable to:
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TAKE ADVANTAGE OF COMMUNITY ACCESS
CONTINUED FROM PAGE 10

are also sent to other community-access facilities around Oregon and air in many other communities besides the Portland/Metro area. Although this process works very well for people on cable and in the viewing area, not everyone has cable.

Money was raised to duplicate many of the master broadcast tapes so that videotapes for a home VCR could be placed in many public libraries around the state. Thus, the tapes are now reaching not only polio survivors, but people with other types of disabilities as well.

Interested in reaching out to more polio survivors? Check with your cable company to find out what services and facilities they have to offer locally. Some may have the full range of facilities such as TVCA, which offers training, technical assistance, the use of studio and equipment, and the ability to check out equipment to do a field shoot or the use of a production van. A nominal cost may arise according to your local facility.

And that's a wrap!

Contact: Sheila Maxwell, Easter Seal Society of Oregon, 5757 Macadam Avenue, Portland, Oregon 97201 (503/228-5108).

Moving???

Please send your old and new addresses to:

International Polio Network
4207 Lindell Blvd., #110
St. Louis, MO 63108-2915

Phone: 314/534-0475 FAX: 314/534-5070
e-mail: gini_intl@msn.com

calendar

1997

Been There, Done That, Movin' On, SEPTEMBER 12-13, Atlanta, Georgia. Contact: Atlanta Post-Polio Association, P.O. Box 250566, Atlanta, Georgia 30325 (404/350-7631; 770/232-7178 FAX; laslinda@mindspring.com).



Ohio Polio Network Annual Meeting, OCTOBER 11, Ohio University, College of Osteopathic Medicine, Athens, Ohio. Contact: David Livingston, 33001 Fern Tree Lane, North Ridgeville, Ohio 44039 (216/641-6000, ext. 504).



Post-Polio Syndrome: Past, Present, and Future — The Role of Rehabilitation, OCTOBER 18, Royal Sonesta Hotel, Cambridge, Massachusetts. Contact: Harvard Continuing Education (617/432-1525 or <http://www.med.harvard.edu/conted/>).



Fourth Forum Luncheon (Guest Speakers Leo Frangipane, MD, and Joan L. Headley), NOVEMBER 2, Holiday Inn, Bethlehem, Pennsylvania. Contact: Beverly Solomon, 924 N. 33rd Street, Allentown, Pennsylvania 18104 (610/398-3958).