

# 福 Rehabilitation Gazette

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## Update on Ventilator Issues

SEVERAL REPRESENTATIVES, including Oscar A Schwartz, MD, St. Louis, MO, Barry Make, MD, Denver, CO, and Geoffrey Waters, President and Chief Operating Officer of LIFECARE, Lafayette, CO, met with the policy director of the Health Care Financing Administration (HCFA), Bob Wren, in November, 1993.

Three conclusions were reported by Geoffrey Waters:

■ Multiple ventilator users prior to December 1, 1993, will be grandfathered into the system. This means that if you currently have multiple ventilators then you will continue to receive the benefit of multiple ventilators after December 1, 1993.

■ Bob Wren will inform the local Medical Directors of the Regional Carriers that there is no national policy prohibiting multiple ventilator benefits, therefore, the avenue is open for the Regional Directors to make policy decisions for new applications after December 1, 1993, on a local level. There will be no road blocks from the Health Care Financing Administration in Washington, DC.

■ Bob Wren recognized the need to establish a national policy for reimbursement of multiple ventilators and has indicated that he would gather a team to hash out those medical conditions for which multiple ventilators would be provided.

G.I.N.I. would like to thank all who wrote letters to their legislators and to the medical directors of the four regions. Your cogent and straightforward letters

made a difference. We will keep you informed as the process of establishing a national policy for reimbursement of multiple ventilators continues.

SEVERAL OF YOU who receive financial assistance from the March of Dimes for costs related to ventilator use contacted us regarding "the request for financial assistance for polio" form that was received from LIFECARE/March of Dimes. The following is excerpted from a letter from Marcia C. Stein, Director of Media Relations, March of Dimes Birth Defects Foundation National Headquarters.

"Thank you for your query concerning the March of Dimes' request for household income and health insurance information which was sent to polio patients receiving financial support from the foundation.

"The March of Dimes has given financial assistance to polio patients for more than 50 years, providing respiratory equipment and maintenance to anyone requesting it. Presently about 350 people receive assistance through this program which is implemented through a company called LIFECARE.

"Last year, as a result of rapidly rising costs for the equipment, we reviewed our longstanding policy of open-ended financial assistance to polio patients without regard to their financial circumstance or insurance coverage. We determined that limited March of Dimes funds should be used only when private or public health insurance was not available to pay costs.

"The financial information requested will help us determine

if we are the payor of last resort for each patient. It will also enable us to structure a new contract with LIFECARE and recertify each applicant, a usual procedure for providers of financial aid. LIFECARE is helping patients qualify for other assistance.

"Following completion of the process, scheduled for next April, patients will be notified of any changes in the level of support they receive from the March of Dimes."

G.I.N.I. HAS ALSO BEEN ASKED several times if we have compiled and/or published guidelines for personal assistants/caregivers of persons using a ventilator at home. We have not. Additional questions asked include: Does the caregiver need to be licensed? Does licensing of the caregiver depend on whether the user is using non-invasive ventilation or invasive ventilation? Doesn't requiring guidelines for assistants/caregivers increase the cost of living at home on a ventilator? What about liability? Who does the training? Etc., etc.

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### Inside This Issue...

**For the Sixth International Post-Polio and Independent Living Conference**  
St. Louis, Missouri USA  
June 16-19, 1994

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## MORE VENTILATOR ISSUES

*G.I.N.I. is receiving more and more calls and letters from individuals with disabilities who are aging and whose caregivers are aging also. They are looking for information, resources, suggestions, and creative solutions to several issues such as transportation, personal assistance, and, in particular, housing. Your thoughts, comments, and solutions are welcomed. One solution is shared below.*

**B**arbara Fort, age 66, from Montgomery County, Missouri, had polio in 1949 after the birth of her first daughter. She spent six months in the Central Missouri Polio Hospital — one month in the iron lung. She and her husband, Doe, raised five children.

In 1985, after complete respiratory failure, she was trached and placed on a PLV-100 24 hours a day. Doe was trained on how to care for her tracheostomy and her ventilator.

Over the next few weeks Doe's health deteriorated, and because of Barbara's recurrent infections, her physician felt a nursing home was the answer. Barbara and Doe found, after research, that the only home accepting ventilator-assisted individuals in their area was at Marceline, Missouri, over 100 miles from their home. Barbara states, "It was inconceivable to think I would have to go so far away from my home. I knew that if I was to recover, I needed to be among people, friends, and family whom I love."

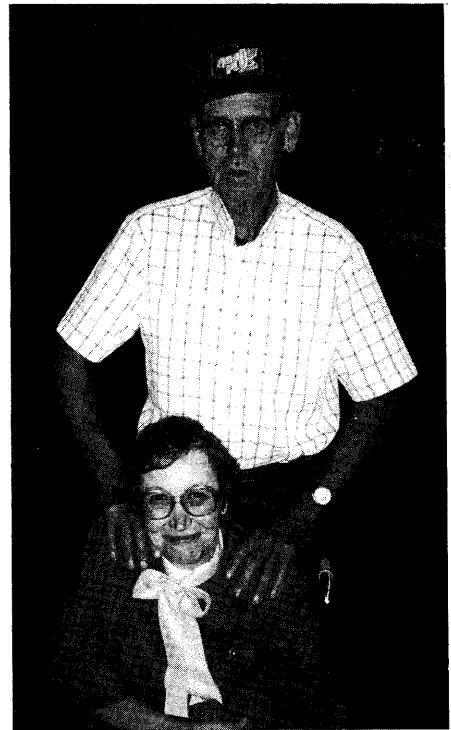
The Gamma Road Lodge, a nursing home in her home town, had 60 skilled and 60 unskilled beds and was also VA approved. The administration felt they were not qualified to care for a ventilator-assisted individual. Barbara recalls, "It seemed fear was the greatest barrier. But to me, if my husband could be trained, surely the nurses who had nursing degrees could do the same." Her primary care physician, the medical director of the facility,

was very concerned about her dilemma. He, along with her daughter, persuaded the administration to accept her. The LPN's and RN's were trained, and she entered Gamma Road Lodge while on the ventilator 24 hours a day.

Consequently, her condition stabilized, and she now uses the ventilator at night experiencing an occasional infection. "I go on the ventilator about 10:00 P.M. and take myself off about 7:00 A.M. I go home every day, weather permitting, and return to Gamma Road Lodge in the evening after spending the day with Doe. He and I both rest comfortably each night. I have the best of two worlds."

**G**amma Road Lodge was built and established in 1979. Edna Berry, RN, began work at that time and has held various nursing positions at the facility. When the call came from the Director of Nursing that Barbara Fort was to be admitted to her facility, Edna was surprised and frightened. Being from a small community she knew Barbara; knew about her tracheostomy and ventilator. Her mind flew back to nursing school. What did she know about ventilators? She had very little experience with them in school and absolutely none since.

The day Barbara was admitted to the facility, the staff was comfortable and knowledgeable about her care and the ventilator because they had been trained by a respiratory therapist from Clasen Home Health Care. She taught them how to



**Barbara and Doe Fort**

suction the trach and change the dressing; to operate the ventilator; to keep the 800 number of Clasen close by. Edna remembers, "Barbara was great. She guided us through each step with her assistance and confidence. During the seven years Barbara has been at Gamma Road Lodge, she has become a dear friend and a true asset, and is very active as president of the residence council." ■

*Any questions will be gladly answered by Barbara Fort, or Edna Berry, RN, Gamma Road Lodge, #250 Gamma Road, Wellsville, MO 63384.*

**The 1994 Sister Kenny Institute International Art Show** will open April 15, 1994 and close May 15, 1994. Deadline for receiving art is March 7. For more details, contact Art Show Public Relations Dept., Sister Kenny Institute, 800 E. 28th St., Minneapolis, MN 55407-3799.

## Medicare Covers Skilled Health Care at Home

If you're a Medicare beneficiary who needs skilled health care in your own home, Medicare may pay the costs if you use a participating home health agency. If you think you're eligible, your doctor can refer you to a participating local agency that will see if you meet the requirements. That agency will evaluate your case free of charge.

A home health agency may be a public or private agency. It specializes in providing skilled nursing services and therapeutic services — like physical therapy — to individuals confined to their homes. If you live in a hospital or a facility that mainly provides skilled nursing or rehabilitation services, it's not considered to be your "home." Therefore, Medicare will not pay the cost of home health services in that residence.

### **To be eligible for home health visits, you must meet all four of the following conditions:**

- You must need care that includes intermittent skilled nursing care, physical therapy, or speech/language therapy;
- You must be confined to your home;
- Your physician must determine that you need home health care and must set up a home health plan for you; and
- The agency providing your home health services must participate in Medicare.

If you meet all four conditions, Medicare will pay the full approved cost for all medically required covered services — except for a 20-percent copayment for durable medical equipment such as wheelchairs or oxygen equipment. If you need occupational therapy at home even after you no longer need

intermittent skilled nursing care, physical therapy, or speech/language therapy, Medicare will continue to pay for the covered services.

It's important to remember that general household services — someone to do the laundry, prepare meals, or do your shopping — are not covered by Medicare. Nor are other home care services that mainly meet personal, family, or domestic needs.

### **Here's what Medicare covers:**

- Part-time or intermittent skilled nursing care (that may include up to eight hours of reasonable and necessary care per day for up to 21 consecutive days — or longer in some circumstances);
- Physical therapy, and
- Speech therapy.

### **In conjunction with these covered services, Medicare also may pay for:**

- Occupation therapy;
- Part-time or intermittent home health aide services;
- Medical social services;
- Medical supplies; and

■ 80 percent of the approved cost of durable medical equipment (including items such as oxygen equipment, wheelchairs, and other medically necessary equipment prescribed by your doctor for your use at home).

If you receive home health care, the participating agency will submit its claim for payment directly to Medicare. You don't have to send in any bills.

More information about Medicare can be found in *The 1993 Medicare Handbook*. The handbook is mailed to all newly eligible Medicare beneficiaries. If you don't have a copy, you can get one from your local Social Security office or by writing to the Consumer Information Center, Department 70, Pueblo, CO 81009. The handbook is revised each year, but updated copies are not mailed to all Medicare beneficiaries unless major program changes are made. ■

**Source:** Social Security Courier, U. S. Department of Health and Human Services, Social Security Administration.

*The 1994 Post-Polio Directory* is currently being updated. The *Directory* contains four sections. The International section lists contacts in countries throughout the world interested in post-polio and disability issues. The entries for the U.S. are divided into three categories. Physicians and facilities providing specialized and comprehensive treatment for polio survivors are listed under Clinics. Many individual health professionals have expertise in treating polio survivors and are listed along with their areas of medical specialties under Health Professionals. The Support Group section lists support groups, along with a contact person. Some names listed are resource only and are designated as such.

Health professionals listed in the *Directory* are specialists and are not intended to replace a primary care physician. A recent letter to G.I.N.I. points out another post-polio problem. The long-time, primary care physicians of polio survivors are now retiring. Survivors are having to search for new ones. Where does one start? What does one look for? How does one find a physician who understands and treats long-term disability? Readers are invited to share their thoughts and experiences.

Many individuals start their search for post-polio information with us. Please send additions, corrections, and deletions to G.I.N.I., 5100 Oakland Ave., #206, St. Louis, MO 63110-1406 or FAX to 314/534-5070.

*The 1994 Directory* will be available March 1, 1994.

**Due to the Sixth International Post-Polio and Independent Living Conference June 16-19, 1994, the June 1994, *Rehabilitation Gazette* will not be published until late July.**

**G.I.N.I.** has been publishing since the 1950s. Copies of *Toomeyville Gazette*, *Toomey j Gazette*, and the *Rehabilitation Gazette* reveal that through the years individuals who had polio have been called polio patients, wheelchair patients, polios, iron lung polios, multipletics, respos, horizontals (severely disabled) vs verticals (non-disabled), upside down polios, polio quads, handicapped, physically handicapped, disabled, post-polio people, and polio survivors.

The 1980 *Rehabilitation Gazette* (Vol. XXIII) contained the article "Watch Our Words" noting that 1981 would be the International Year of Disabled Persons, not "handicapped" persons, or "crippled" persons. The politically correct article argues against generalizing which impersonalizes, negative images which reflect small expectations, words which imply people with disabilities are asexual, and labels which assign super-human qualities.

Since that time, G.I.N.I. publications have consistently used terms such as people with disabilities, ventilator users, and polio survivors, never accepting the euphemistic "physically challenged." Over the years a few readers have expressed their dislike for the term survivor. With a better understanding of what it means to be a survivor, they may change their minds.

In 1993, Al Siebert, PhD, published *The Survivor Personality* (ISBN 0-944227-06-6), in which he describes survivors and their qualities.

Dr. Siebert first became interested in survivors when he served in the Army in the early '50s. Part of his paratrooper training was conducted by individuals in a unit that had sur-

vived capture by communists in Inchon. He realized that these survivors had characteristics "which tipped the scales in their favor." He "decided to work backward. I look for people who had survived a major, stressful personal crisis which was surmounted in some way by their own personal effort, and which resulted in them being stronger and more capable than they were before."

Dr. Siebert interviewed "hundreds of people, survivors of the World War II Bataan Death March; Jewish survivors of the Nazi Holocaust; ex-POWs and Vietnam veterans; survivors of cancer, polio (he spoke with Ed Roberts and Dorothy Woods Smith), head injury, and other physically challenging conditions; survivors of co-dependency, abuse, alcoholism, and addiction; parents of murdered children ..."

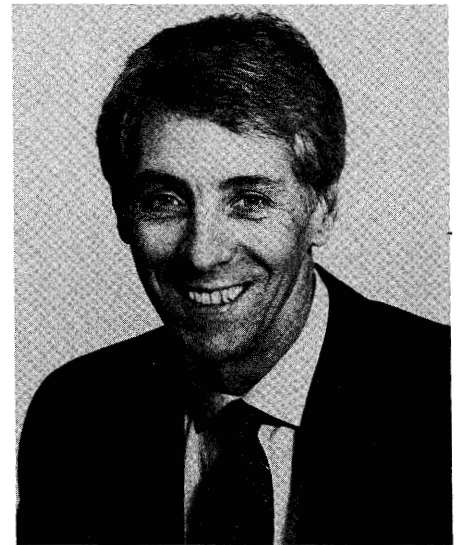
The following extended excerpt from his book describes what he learned:

"I learned that most survivors are ordinary people with flaws, worries, and imperfections. When people call them heroes they disagree. 'We just did what any reasonably sensible people would have done,' say two women who were lost for a week in the mountains during freezing winter weather. 'We aren't heroes,' they keep saying to people awed by their survival.

"I learned that a few good people are born survivors. They are the natural athletes in the game of life. Just as some people are born musicians, writers, artists, or singers, some people are gifted in living. The rest of us need to consciously work to develop our abilities. Just as we would have to take lessons and practice diligently to become artists or musicians, we have to work at learning how to handle

job pressures, difficult people, conflict, negative situations, unwelcome change, and crises.

"I learned that some of life's best survivors grew up in horrible family situations, and that many of the people least skillful at coping with life's difficulties have come from ideal homes. Many of the best people in our world have been through experiences that no public school could get away with arranging. They have been strengthened in the school of life. They have been abused, lied to, deceived, robbed, mistreated, and hit by the worst that life can throw at them. Their reaction is to pick themselves up, learn important lessons, set positive goals, and rebuild their lives.



**Al Siebert, Ph.D.**

"I learned that people seldom tap into their deepest strengths and abilities until forced to do so by a major adversity. As Julius Segal, the distinguished survivor researcher has said, 'In a remarkable number of cases, those who have suffered and prevail find that after their ordeal they begin to operate at a higher level than ever before ... The terrible experiences of

continued on page 15



## **SIXTH INTERNATIONAL**

# **Post-Polio and Independent Living Conference**

**St. Louis, Missouri USA ■ June 16-19, 1994**  
**St. Louis Marriott Pavilion**

### **CONFERENCE PROGRAM AND REGISTRATION FORM**

■ The program includes a special session for first-time attendees on Thursday morning featuring original polio, post-polio theories, and G.I.N.I. Plenary sessions planned for Thursday afternoon, Friday morning, and Saturday afternoon will cover, in part, orthopedic and breathing problems, research, and health care reform. Friday afternoon offers four choices — Energy Conservation and Lifestyle Enhancement, Disability in Perspective, Forum for Ventilator Users, and Forum for Support Group Coordinators. Saturday morning provides a dozen choices. The next two pages feature the program overview.

■ Sessions are presented by panels composed of both professionals and consumers. A listing of the confirmed panelists follows the program overview.

*Sponsored by Gazette International Networking Institute, coordinator of International Polio Network, and International Ventilator Users Network.*

With special thanks for financial assistance from:

G.I.N.I. Friends and Contributors

Hope Thomson Bequest

LIFECARE INTERNATIONAL, INC.

March of Dimes

Provide Medical Equipment Supply, Inc.

Respironics Inc.

and Panelists who donate their time and expertise



# PROGRAM OVERVIEW

(Subject to change)

**JUNE 15, 1994**

## Wednesday Evening

3:30-5:30 pm  
Registration

**JUNE 16, 1994**

## Thursday Morning

8:30 am - 1:30 pm  
Registration

9:30-11:30 am  
**FOR FIRST-TIME ATTENDEES**

G.I.N.I. Then and Now  
Post-Polio Syndrome  
101: Acute Polio &  
Post-Polio Theories

11:30 am - 1:30 pm • LUNCH

## Thursday Afternoon

1:30-3:00 pm  
**PLENARY SESSION**

Status of Polio in the  
World Today  
Defining Post-Polio  
Problems  
Incidence and Prevalence  
of Post-Polio Problems

3:30-5:00 pm  
**PLENARY SESSION**

Coordinating Post-Polio  
Treatment: You, Your  
Primary Physician and  
Your Expectations  
The Battle with Bracing

## Thursday Evening

6:30 pm • DINNER  
*Why Survivors Survive*  
Al Siebert, PhD

**JUNE 17, 1994**

## Friday Morning

7:30-8:30 am • Registration

8:30-9:45 am  
**PLENARY SESSION**

Post-Polio Corrective  
Surgery: Then and Now  
Recovery from  
Orthopedic Injury

10:15-11:30 am  
**PLENARY SESSION**

Facing Surgery When  
Breathing Is a Problem  
New Breathing Problems  
in Aging Polio Survivors  
New Swallowing Problems  
in Aging Polio Survivors

11:30 am - 1:30 pm • LUNCH

## Friday Afternoon

1:00-1:30 pm • Registration

1:30-5:00 pm • **SESSION I**  
*Energy Conservation and  
Lifestyle Enhancement*

1:30-3:00 pm  
Finding Your Personal  
Threshold  
Determining Prescribed  
Activity

3:30-5:00 pm  
Choosing Correct  
Equipment  
Adapting to Using  
Adaptive Equipment  
Ideas for Relaxing

## Friday Night in St. Louis ...

## Saturday Morning

8:00-9:00 am • Registration

9:00-10:00 am • **SESSIONS A-K**

<b>SESSION A</b>	<b>SESSION B</b>	<b>SESSION C</b>
Challenges Facing Individuals with Disabilities	Update on Social Security	Face Masks Show and Tell & Frog- breathing Lessons

10:30-11:30 am

Continuation of Sessions A, C and D;  
Repeat of all others

11:30 am - 1:30 pm • LUNCH

1:30-5:00 pm • **SESSION II**  
*Disability in Perspective*

1:30-3:00 pm  
Disability as a Life Course:  
Theory and Research  
Separating Post-Polio Syndrome  
from Aging: Can It Be Done?  
Disability as a Life Course:  
The Implications

3:30-5:00 pm  
"Girl in the Yellow Dress"  
From My Perspective  
Secondary Disability:  
My Family and Me

Contact St. Louis Convention  
and Visitors Commission  
(800/888-FUN1).

# THE SIXTH INTERNATIONAL POST-POLIO & INDEPENDENT LIVING CONFERENCE

**JUNE 18, 1994**

<b>SESSION D</b>	<b>SESSION E</b>	<b>SESSION F</b>	<b>SESSION G</b>	<b>SESSION H</b>	<b>SESSION I</b>	<b>SESSION J</b>	<b>SESSION K</b>
Dealing with Chronic Pain	Other Therapies for Post- Polio	Post-Polio Clinics: Goals and Approaches	Dealing with Inconti- nence	Polio History: Our Stories Must Be Told	Care and Maintenance of Your Ventilator	Under- standing EMGs	Resources for the Aging Population

## Saturday Afternoon

1:00-1:30 pm • Registration

1:30-3:00 pm  
**PLENARY SESSION**

Post-Polio Research: What's Being  
Done and What Needs to Be Done

3:30-5:00 pm  
**PLENARY SESSION**

Health Care Reform: Its Impact  
on People with Disabilities

Health Care Reform: Caveats  
from International Participants

## Saturday Evening

7:00 pm • DINNER AND DANCE

*A Celebration with Friends*

**JUNE 19, 1994**

## Sunday Morning

10:00 am • BRUNCH

1:30-5:00 pm • **SESSION III**  
*Forum for Ventilator Users*

1:30-3:00 pm

Improving Cough and  
Decreasing Infection

Changing Equipment  
as Diagnoses Change in  
Muscular Dystrophy,  
SCI, and CCHS

Diaphragmatic Pacer:  
What, Who, and When

3:30-5:00 pm

Living at Home:  
Overcoming Obstacles

1:30-5:00 pm • **SESSION IV**  
*Forum for Post-Polio  
Coordinators*

Networking G.I.N.I. Style

What, How, and Why's  
of Facilitating

Sharing Your Group's  
Success

T St. Louis Cardinals will be playing the  
Pittsburgh Pirates —  
Contact Busch Stadium 314/421-3060.



# PANELISTS

## June 16, 1994, Thursday Morning

Joan L. Headley, G.I.N.I., St. Louis, MO  
Frederick M. Maynard, MD, MetroHealth  
Center for Rehabilitation, Cleveland, OH  
Martin B. Wice, MD, St. John's Mercy Medical  
Center, St. Louis, MO  
Stanley K. Yarnell, MD, St. Mary's Hospital,  
San Francisco, CA

## Thursday Afternoon

Neil R. Cashman, MD, Montreal Neurological  
Institute, Montreal, Quebec  
Lauro S. Halstead, MD, National  
Rehabilitation Hospital, Washington, DC  
Robert A. Keegan, Public Health Adviser,  
Centers for Disease Control, Atlanta, GA  
Frederick M. Maynard, MD, MetroHealth  
Center for Rehabilitation, Cleveland, OH  
P.E. Parsons, PhD, MPH, National Center for  
Health Statistics, Hyattsville, MD  
Jacquelin Perry, MD, Rancho Los Amigos  
Medical Center, Downey, CA  
Jonathan M. Ramlow, PhD, MPH,  
Dow Chemical Co., Midland, MI  
Albert Esquenzai, MD, Moss Rehabilitation,  
Philadelphia, PA  
Marny Eulberg, MD, Mercy Medical Center,  
Denver, CO  
John R. Fisk, MD, Southern Illinois University,  
Springfield, IL  
Glenn Ham-Rosebrock, CO, Ortho Kinetics,  
Downey, CA  
Dorothy Woods Smith, PhD, RN,  
University of Southern Maine, Westbrook, ME  
Stanley K. Yarnell, MD, St. Mary's Hospital,  
San Francisco, CA  
Armand Zilioli, MD, PA, Winter Park, FL

## June 17, 1994, Friday Morning

Mary Ann Keenan, MD,  
Albert Einstein Medical Center, Philadelphia, PA  
NICKIE LANCASTER, Hermitage, TN  
Jacquelin Perry, MD,  
Rancho Los Amigos Medical Center, Downey, CA  
Sunny Roller, MA,  
University of Michigan, Ann Arbor, MI  
Irwin M. Siegel, MD, Rush Presbyterian  
St. Luke's Medical Ctr., Chicago, IL  
Ensor E. Transfeldt, MD, University of  
Minnesota, Minneapolis, MN  
Augusta S. Alba, MD,  
Goldwater Memorial Hospital, New York, NY  
Carl A. Coelho, PhD, Gaylord Hospital,  
Wallingford, CT  
Kathleen A. Navarre, PhD, Delta College,  
University Center, MI  
Ann Romaker, MD, Romaker and Associates,  
Kansas City, MO  
Oscar A. Schwartz, MD, PC, St. Louis, MO

## Friday Afternoon • Session I

Rubin Feldman, MD, MacKenzie Health  
Sciences Center, Edmonton, Alberta  
Lauro S. Halstead, MD, National  
Rehabilitation Hospital, Washington, DC  
Greg Nemunaitis, MD,  
Medical College of Ohio, Toledo, OH  
Marianne T. Weiss, LPT,  
Community Physical Therapy, Canton, OH  
Martin B. Wice, MD,  
St. John's Mercy Medical Center, St. Louis, MO  
Nancy Caverly, OTR, Bland, MO

Hannah Hedrick, PhD,  
American Medical Association, Chicago, IL  
Robert B. McCown, PhD, Engineer, Columbus, OH  
Sunny Roller, MA,  
University of Michigan, Ann Arbor, MI  
Grace R. Young, OTR,  
Kaiser Permanente, Downey, CA

## Friday Afternoon • Session II

Margaret L. Campbell, PhD  
RRTC on Aging with Disability, Downey, CA  
Linda Bieniek, CEAP, Chicago, IL  
Steven P. Dinsmore, DO,  
Center for Aging, Stratford, NJ  
Jack Genskow, PhD,  
Sangamon State University, Springfield, IL  
Frederick M. Maynard, MD, MetroHealth  
Center for Rehabilitation, Cleveland, OH  
Jessica Scheer, PhD, National Rehabilitation  
Hospital, Washington, DC  
Mary Westbrook, PhD,  
Chatswood, New South Wales, Australia  
Margaret E. Backman, PhD, New York NY  
Karen Donovan, MSW, Los Angeles, CA  
Thomas Hale, Williamsburg, VA  
Paul A. Hasak, PhD, St. Louis, MO  
Robert Ronald, SJ,  
Operation De-Handicap, Taipei, Taiwan  
Joyce A. Tepley, Dallas, TX

## Friday Afternoon ■ Session III

Augusta S. Alba, MD,  
Goldwater Memorial Hospital, New York, NY  
John R. Bach, MD,  
University of Medicine and Dentistry, Newark, NJ  
William H. Dobelle, PhD,  
The Dobelle Institute, Glen Cove, NY  
Daniel M. Goodenberger, MD,  
Washington University, St. Louis, MO  
Sue Sortor Leger, RRT, Lyon, France  
Joseph Viroslav, MD,  
Dallas Rehabilitation Institute, Dallas, TX  
Patrick Leger, MD,  
l'Hopital de la Croix Rousse, Lyon, France  
George B. Mallory, Jr., MD,  
Washington University, St. Louis, MO  
Mickie McGraw, Cleveland, OH  
Virginia Nelson, MD,  
University of Michigan, Ann Arbor, MI  
Margaret A. Nosek, PhD, Baylor College,  
Houston, TX  
Edward A. Oppenheimer, MD, SO. CA  
Permanente Medical Group, Los Angeles, CA  
Mary Ann Sevick, ScD, RN, Pittsburgh, PA

## Friday Afternoon • Session IV

Joan L. Headley, G.I.N.I., St. Louis, MO  
Elizabeth Purcell, The Purcell Group, Training  
& Organizational Development, St. Louis, MO

## June 17, 1994,

## Saturday Morning • Session A

Angelique Lair-Greve, PhD,  
Auburn University, Auburn AL  
Lori Hinderer, St. Louis, MO  
Margaret A. Nosek, PhD,  
Baylor College, Houston, TX  
Max J. Starkloff, Paraquod, St. Louis, MO  
Diane E. Woods, IIEIR, Durham, NH

## Saturday Morning • Session B

J. Kenneth McGill,  
Social Security Administration, Baltimore, MD  
Douglas M. Smith,  
Physicians' Disability Services, Inc., Arnold, MD

## Saturday Morning • Session C

Augusta S. Alba, MD,  
Goldwater Memorial Hospital, New York, NY  
John R. Bach, MD,  
University of Medicine and Dentistry, Newark, NJ  
Nancy Nicoll, Respronics Inc., Murrysville, PA  
Shelley Morris-Tomazevic, RRT  
Dallas Rehabilitation Institute, Dallas, TX  
Vera Overholt, Minerva, OH  
Wilma Pierce, RRT,  
Dallas Rehabilitation Institute, Dallas, TX  
Oscar A. Schwartz, MD, FCCP, PC,  
St. Louis, MO

## Saturday Morning • Session D

Richard T. Katz, MD,  
SSM Outpatient Rehab, St. Louis, MO  
Katherine Mitchell, St. Louis, MO  
Kenneth Russ, PhD, St. Louis, MO  
Marianne Weiss, LPT,  
Community Physical Therapy, Canton, OH  
Dorothy Woods Smith, PhD, RN,  
University of Southern Maine, Westbrook, ME

## Saturday Morning • Session E

F. T. H'Doubler, Jr., MD, Springfield, MO  
Ed Snapp, PT, Futures Unlimited, Columbus, MS

## Saturday Morning • Session F

Rubin Feldman, MD, MacKenzie Health  
Sciences Center, Edmonton, Alberta  
Mary Ann Keenan, MD, Albert Einstein  
Medical Center, Philadelphia, PA

## Saturday Morning • Session G

Vicki Johnson, RN, MSN, TTUHSC School of  
Nursing, Lubbock, TX

## Saturday Morning • Session H

Karen Hirsch, Northeast Missouri State University,  
Kirksville, MO

## Saturday Morning • Session I

Jerry Daniel, VENTEK, Vancouver, WA

## Saturday Morning • Session J

Martin B. Wice, MD,  
St. John's Mercy Medical Center, St. Louis, MO  
Roberta Simon, RN, Darien, IL

## Saturday Morning • Session K

Margaret L. Campbell, PhD,  
RRTC on Aging, Downey, CA

## June 18, 1994, Saturday Afternoon

Lauro Halstead, MD,  
National Rehab Hospital, Washington, DC  
Burk Jubelt, MD,  
SUNY Health Science Center, Syracuse, NY  
Roberta Simon, RN, Darien, IL  
Pat Harvey, Missouri Citizen Action, St. Louis, MO  
Judith E. Heumann, Asst. Secretary, Office of  
Special Education and Rehabilitation Services  
(OSERS), Washington, DC  
Edward A. Oppenheimer, MD, So. Calif.  
Permanente Med. Group, Los Angeles, CA  
Martin B. Wice, MD,  
St. John's Mercy Medical Center, St. Louis, MO  
Stanley K. Yarnell, MD, St. Mary's Medical  
Center, San Francisco, CA



# REGISTRATION FORM

Sixth International Post-Polio and Independent Living Conference  
June 16-19, 1994 ■ St. Louis Marriott Pavilion Hotel

DEADLINE: May 15, 1994

Mall or FAX to:  
Gazette International Networking  
Institute (G.I.N.I.)  
5100 Oakland Ave., #206  
St. Louis, MO 63110-1406  
Phone: 314/534-0475  
FAX: 314/534-5070

Date: \_\_\_\_\_, 1994

Name: \_\_\_\_\_ Degree(s) \_\_\_\_\_  
          First                          Middle Initial                          Last

Institution: \_\_\_\_\_

Address: Check one.  home  business

Street: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zipcode: \_\_\_\_\_ - \_\_\_\_\_ Country \_\_\_\_\_

Phone: Check one.  home  business \_\_\_\_\_ FAX: \_\_\_\_\_

## REGISTRATION (Includes continental breakfast on Friday and Saturday. See MEALS for lunch and dinner.)

### Full Registration:

	Prior to April 25	After April 25
Individual with disability	<input type="checkbox"/> \$110	<input type="checkbox"/> \$130
Individual with disability and one attendant/family (name for badge) _____	<input type="checkbox"/> \$170	<input type="checkbox"/> \$190
Health Professional and Others	<input type="checkbox"/> \$220	<input type="checkbox"/> \$240

### Single Day Registration (includes continental breakfast; see MEALS for lunch):

Individual with disability: <input type="checkbox"/> Thursday <input type="checkbox"/> Friday <input type="checkbox"/> Saturday	(\$40/day) \$ _____	(\$45/day) \$ _____
Individual with disability and one attendant/family: (name for badge) _____ <input type="checkbox"/> Thursday <input type="checkbox"/> Friday <input type="checkbox"/> Saturday	(\$60/day) \$ _____	(\$65/day) \$ _____
Health Professional and Others <input type="checkbox"/> Thursday <input type="checkbox"/> Friday <input type="checkbox"/> Saturday	(\$80/day) \$ _____	(\$85/day) \$ _____

*In the event of cancellation, we will be able to refund 85% of the registration fee if cancellation is made by written notice before May 15th. Registration will not be refunded after May 15th.*

For program accessibility, please list your special needs

(for example, braille materials, interpreter, etc.) \_\_\_\_\_

Registration Sub-Total \$ \_\_\_\_\_

### Meals:

The complete meal package fee of \$100 per person includes Thursday and Saturday dinners and Friday and Saturday lunches. Please note if you have dietary restrictions. (There is no dinner planned for Friday evening. Continental breakfasts are included in registration fee).

\_\_\_\_\_ Meal Packages @ \$100

### Individual meals:

- Thursday lunch (after first-time attendees meeting) \$20
- Thursday dinner \$30
- Friday lunch \$20
- Saturday lunch \$20
- Saturday dinner \$32
- Sunday morning brunch \$16

Meals Sub-Total \$ \_\_\_\_\_

Registration Sub-Total \$ \_\_\_\_\_

TOTAL \$ \_\_\_\_\_

(continued on reverse side)

**PAYMENT OF FEES**

- Check or Money Order (U.S. dollars only, payable to G.I.N.I.)
- Mastercard  Visa Card Number \_\_\_\_\_

Name on card (*please print*) \_\_\_\_\_

Expiration Date \_\_\_\_\_

Signature \_\_\_\_\_

**My choice for Friday afternoon is:**

- Session I — Energy Conservation and Lifestyle Enhancement
- Session II — Disability in Perspective
- Session III — Forum for Ventilator Users
- Session IV — Forum for Post-Polio Coordinators

**My choice for Saturday A.M. is:**

*(Please choose one two-hour session, or two one-hour sessions.)*

- Session A — Challenges Facing Individuals with Disabilities (two-hour)
- Session B — Update on Social Security
- Session C — Face Masks Show and Tell & Frogbreathing Lessons (two-hour)
- Session D — Dealing with Chronic Pain (two-Hour)
- Session E — Other Therapies for Post-Polio
- Session F — Post-Polio Clinics: Goals and Approaches
- Session G — Dealing with Incontinence
- Session H — Polio History: Our Stories Must be Told
- Session I — Care and Maintenance of Your Ventilator
- Session J — Understanding EMGs
- Session K — Resources for the Aging Population

**FOR OFFICE USE ONLY**

<p><b>PR</b></p> <p>C</p> <p>MO</p> <p>CC</p>		<p><b>RD</b></p>
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# GENERAL INFORMATION

## TRANSPORTATION

There is no official airline for the conference. However, Southwest Airlines is offering attendees a discount on both Southwest's low everyday unrestricted fares and Southwest's even lower restricted fares. To take advantage of these discounts, reservations must be made by phoning Southwest Airlines Group Desk at 800/433-5368, Monday-Friday, 8am-5pm. (Because advance bookings are accepted by Southwest only through the dates for which schedules have been finalized, reservations may not yet be available for confirmation.) Call by June 3, 1994 and refer to identifier code **V52**.

**TAXIS** are available at Exit 13 on the baggage level. The fee will be

approximately \$20 one way.

Several taxi companies have lift-equipped vans and will transport individuals from the airport to downtown. The fee ranges from \$18 to \$25 one way. To make arrangements contact one of the following: ABC Paratransit, call Ray at 314/520-3462 or 314/851-2842; B&B Taxi and Paralift, call Linda Brumbaugh at 314/429-6644 several days prior to arriving in St. Louis; Richardson Transportation, call as soon as possible, or one day ahead at 314/725-9111. Care Cab (314/644-1163) costs \$40 one way per wheelchair.

**Airport Express** (314/429-4950) is the limousine service to the downtown hotels. They are located at Exit 13 (inside) on the bag-

gage claim level. The fee is \$8 one way, or \$14 round trip. The service has lift-equipped vans. Those planning to use Airport Express are advised to send (or call 314/429-1114) their name, etc., and approximately arrival and departure times to Carolyn, P.O. Box 10038, Lambert Field, St. Louis MO 63145.

## VENTILATORY EQUIPMENT

Individuals needing assistance with ventilatory equipment should make arrangements by May 13, 1994 with Mr. Jeff Davis, LIFECARE, 110 Northwest Parkway, Riverside, MO 64150 (800/669-9234 or 816/741-7667, FAX 816/741-4853). If you need a rocking bed or iron lung, please notify Mr. Davis by April 15, 1994.

## PERSONAL ASSISTANCE SERVICES

Individuals wanting personal assistance services may contact one of the following: Barnes-Jewish Nurses Plus (314/362-4688); Staff Builders Home Health (314/997-2770); Peace of Mind Attendant Care (314/454-0602); or Duane Gruis, Paraquad (314/534-5100).

## HOTEL

Space has been reserved at the St. Louis Marriott Pavilion Downtown, One Broadway, St. Louis, MO 63102 (314/421-1776). The Marriott Pavilion is located just north of Busch Stadium on Broadway (one way going South) and between Market (two way with median) and Walnut (one way East), the street between the Marriott and Busch Stadium.

## PARKING

Valet parking is available at the Broadway entrance (\$12 per day). To park in the hotel garage (\$9 per day), turn right off Market (going East) between the hotel and bank and then left into the

garage. Hotel registration will be available at the garage entrance lobby on Wednesday and Thursday.

Parking is also available in the Stadium Park East garage (314/241-7475) at \$9 per day. Stadium Park East is located at 200 S. Broadway, southeast of the Marriott.

The individuals using MetroLink (\$1) should get off at Busch Stadium. The stop is on the southwest corner of the stadium. The Marriott is to the northeast. (MetroLink will not be completed to the airport until the Fall of 1994. At the time of the conference part of the trip will be via bus. The regular fare is around a dollar one way. If you would like this information contact G.I.N.I.)

- All Thursday and Friday sessions (excluding Session IV) and Saturday afternoon will be audio- and videotaped. A report from Session IV will be made available to facilitators.
- Smoking will not be permitted in the conference meeting rooms.

■ Panelists should register with the hotel now. You will receive a conference registration form with your packet.

■ The daily lunch break will be from 11:30 am to 1:30 pm.

■ The Thursday Dinner speaker will be Al Siebert, PhD. (see page 4)

■ No activities are scheduled for Friday evening. Visitors should contact St. Louis Convention and Visitors Commission (800/888-FUN1). The St. Louis Cardinals will be playing the Pittsburgh Pirates. Contact Busch Stadium 314/421-3060.

■ Saturday evening there will be **A Celebration with Friends** including dinner and music.

# HOTEL INFORMATION

The St. Louis Marriott Pavilion Hotel Downtown, One Broadway, St. Louis, MO 63102 (314/421-1776) will be the site of the Sixth International Post-Polio and Independent Living Conference, June 16-19, 1994. The Marriott meets the requirements of the ADA. The percentage of individuals with disabilities attending the G.I.N.I. conference is high. To assure that we all have an enjoyable stay, we have compiled the following facts about the rooms, and have noted the possible modifications available. We ask that you cooperate with G.I.N.I. and the Marriott in booking your room.

■ The conference meeting rooms are on the 2nd floor, just off of the guest elevators of the West Tower. Individuals who have trouble walking should book in the West Tower.

Individuals who are motorized should book in the East Tower.

■ There are non-smoking floors available in both East and West Towers.

### East Tower Room Information

The regular king rooms are 11 by 19; the queen rooms are 12 by 18; and the regular double/double rooms are 12 by 18. The beds are on pedestals; the clearance is 22 inches high and 80 inches deep. The space by each bed is 29 inches. The bathroom doors are 30 inches wide (the entry door is 36 inches) and opens in. The bathrooms are 5 feet by 7-1/2 feet.

### West Tower Room Information

The regular king rooms are 13 by 15; the queen rooms are 13 by 15; and the regular double/double

rooms are 12 by 17-1/2. The beds are on pedestals; the clearance is 22 inches high and 80 inches deep. The space by each bed is 38 inches. The bathroom doors are 28 inches wide (the entry door is 32 inches) and opens in. The bathrooms are 5 feet by 7-1/2 feet.

■ Shower benches and commode units will be made available as a modification for the regular rooms in both towers.

■ The accessible rooms are 13 x 15-1/2. The beds are on pedestals; the clearance is 22 inches high and 84 inches deep. The space by each bed is 44 inches. The bathroom doors are 36 inches wide (the entry door is 36 inches wide) and opens out. The bathrooms are 6 feet by 9-1/2 feet. ■

**St. Louis Marriott**  
**PAVILION DOWNTOWN**  
 One Broadway  
 St. Louis, Missouri 63102  
 (314)421-1776  
 (PLEASE PRINT OR TYPE)

## Sixth International Post-Polio & Independent Living Conference Hotel Registration Form

**GUEST ROOM  
 RESERVATION  
 REQUEST FORM**

Mr. \_\_\_\_\_  
 Mrs. \_\_\_\_\_  
 Ms. \_\_\_\_\_  
First Last

Address:  Home  Business \_\_\_\_\_

City/State \_\_\_\_\_ Zip \_\_\_\_\_

Phone:  Home  Business \_\_\_\_\_

Firm/Organization: \_\_\_\_\_

Arrival date: \_\_\_\_\_ Day of Week: \_\_\_\_\_

Approximate Time: \_\_\_\_\_  AM  PM

# of Rooms \_\_\_\_\_ # Adults (18 yrs.) \_\_\_\_\_ # Children \_\_\_\_\_

Departure Date: \_\_\_\_\_ Day of Week: \_\_\_\_\_

*To avoid duplications of reservations, please submit only one form when sharing accommodations with one or more individuals.*

Name of Person Sharing Accommodations \_\_\_\_\_

- Reservation request is subject to availability. There is a limited number of rooms set aside for your group.
- Reservation requests will be accepted on a first come — first serve basis.
- In the event rate of room type requested is not available, nearest available rate or room type will be assigned. Alternate hotels will be assigned as necessary.
- All rates are subject to state and local taxes.
- Guest rooms will be available for check-in after 4:00 p.m. Saint Louis time.  
**CHECK-OUT TIME IS 12:00 NOON.**

**ROOM GUARANTEE** — To guarantee your room throughout your stay, a non-refundable first night's deposit will be required. The deposit can be applied by a major credit card or a check.

Credit Card # \_\_\_\_\_

Exp. \_\_\_\_\_

- Amex  Visa  Discover
- Mastercard  Diners Club

Signature X \_\_\_\_\_

**Accommodations & Rates (Please check)**

- Single (one person, one bed - \$82)
- Double (two people, one bed - \$82)
- Double/Double (two people, two beds - \$82)
- East Tower
  - Smoking Floor  Non-Smoking Floor
- West Tower
  - Smoking Floor  Non-Smoking Floor
- No modifications needed
- Will need a shower bench
- Will need a commode unit
- Must have an accessible room

We forwarded copies of G.I.N.I. publications featuring articles of ventilator users living at home successfully, along with the 1993 issues of *Rehabilitation Gazette* (Vol. 33,

Nos. 1 & 2) featuring personal assistance services. We told them we would briefly survey our readers.

Please complete the following questionnaire and return it to

G.I.N.I. Any additional comments which you as a ventilator user and/or attendant would like to share are welcome. We look forward to hearing from our international readers as well.

---

### QUESTIONNAIRE

I use mechanical ventilation:  tracheostomy  noninvasive

0 to 6 hours  7 to 12 hours  13 to 18 hours  19 to 24 hours a day

The care associated with the use of my ventilator is done by:  
*(please check all that apply)*

- myself — I was trained by \_\_\_\_\_
- a live-in family member or friend,  
who was trained by \_\_\_\_\_
- a stop-in family member or friend,  
who was trained by \_\_\_\_\_
- a licensed RN at \$ \_\_\_\_\_ per hour, paid for by \_\_\_\_\_  
and trained by \_\_\_\_\_
- a licensed LPN at \$ \_\_\_\_\_ per hour, paid for by \_\_\_\_\_  
and trained by \_\_\_\_\_
- a licensed RT at \$ \_\_\_\_\_ per hour, paid for by \_\_\_\_\_  
and trained by \_\_\_\_\_
- a personal attendant at \$ \_\_\_\_\_ per hour, paid for by \_\_\_\_\_  
and trained by \_\_\_\_\_

On a scale of 1 to 5 (1 = lowest or least desirable, and 5 = the best), please rank the following regarding the individual(s) listed above:

\_\_\_\_\_ my feeling of confidence \_\_\_\_\_ my feeling of personal control  
 \_\_\_\_\_ my assessment of quality of the care \_\_\_\_\_ my assessment of independent living

What I like most about my current system: \_\_\_\_\_  
\_\_\_\_\_

What I dislike most about my current system: \_\_\_\_\_  
\_\_\_\_\_

My advice to professionals writing guidelines for ventilator use in the home would be: \_\_\_\_\_  
\_\_\_\_\_

My age is: \_\_\_\_\_ The state where I live is: \_\_\_\_\_



## Friends Around the World



**Fatima Mansuri and Joan Headley** in the G.I.N.I. office.

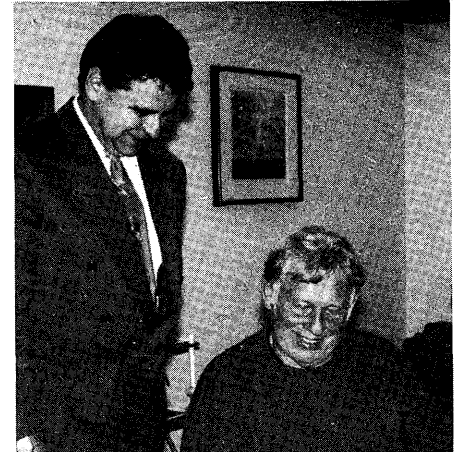
**While visiting family** in the St. Louis area, Fatima Mansuri spent some time in the G.I.N.I. office. She retired as Controllor Program-Sales from the Pakistan Broadcasting Corporation (PBC) in 1989 after 37 years of service. Always active, and now experiencing the consequences of glaucoma, Fatima is involved with disability issues in Pakistan. She is a member of Disabled Peoples' International and would like to network with other disability groups and individuals. Contact Fatima Mansuri, 23/B 5 Central Lane, Karachi, Pakistan.

**Joan Headley** was the luncheon speaker and facilitated a support group session with Sunny Roller at a post-polio conference in Denver, CO in September, 1993. The conference, sponsored by the Colorado Easter Seal Society, was a success due to the hard work of many, particularly Mary Ann Hamilton. Support group coordinators attending from a distance included Elaine Burns, Greater Boston Post-Polio Info/Association, and Mary Wilkinson, Central Virginia.



**Joan Headley and Sunny Roller**

**Ála Wokoun**, polio survivor and long-time contributor to the *Rehabilitation Gazette*, has written a book about his polio. Sveto-beznikem se Sadistkou is available in Czech only, from Ála Wokoun, Chararovicka 1333, 182 00 Prague 8, Czech Republic.



**Roman Koudele, MD, Rehabilitation Institute, Janske Lázně, Czech Republic, and Ála Wokoun, Czech Republic.**

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### Rehabilitation Gazette

*Written by, for, and about individuals with a disability, Rehabilitation Gazette (formerly Toomey J Gazette) has been published since 1958. Its aim is to reach, to inform, and to dignify individuals with disabilities throughout the world.*

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**EDITOR:** Joan L. Headley

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**Elaine Burns**



**Mary Wilkinson**



**Mary Ann Hamilton**

**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 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.

our lives, despite the pain they bring, may become our redemption.'

"Lt. Commander Charlie Plumb, for example, was a navy pilot shot down early in the Vietnam war. He was held in a prison in Hanoi for six years in a stone cell 8 feet by 8 feet in size. He had no window to look out and nothing to read. He was frequently hog-tied, repeatedly beaten, and subjected to grueling interrogations. Yet, in retrospect, when he talks about his experience as a POW he says 'It's probably the most valuable six years of my life. Amazing what a little adversity can teach a person ... I really felt there was some meaning to that, to my experience itself.'

### **Thriving vs. Self-Victimizing**

"I became curious about a fascinating difference in people. Some, like Charlie Plumb, can go through a torturous experience and say 'It was horrible, but it was the most valuable experience of my life.' At the other extreme, some people who are healthy, employed, and living in safe communities with their families, complain about their lives as though they were being tortured.

"The victim style is revealed in statements that repeat this complaint: 'If only other people would change, my life would be better.' There's nothing wrong with that belief, of course, because it's true. Each of us can name several people who would make things better for us if only they would change how they act. It is extremely unlikely, however, that others will voluntarily change themselves to make your life easier. You are the only person on the planet that you can really do something about. Fortunately, you were born with an ability to learn how to handle unfair situations and distressing experi-

ences. You can learn how to respond effectively to life's challenges. You can acquire a learning/coping response as an alternative to feeling like a victim who blames others.

### **"A Teaching Challenge for Me — A Learning Challenge for You**

Years of observing and learning about life's best survivors has convinced me that:

- A survivor style develops out of every day habits that increase chances of survival should it become necessary.
- A survivor style can be learned, but it can't be taught as one would teach a sport or skill.
- People trained to act, think, and feel as instructed cannot cope with life's unexpected challenges as well as a person with a self-discovered personality.

"A frustrating situation for a teacher! How can I teach what can't be taught? How can I offer expert advice about survivorship when people who try to do what an 'expert' says actually lower their chances of coping well with unexpected difficulties?

"My way of handling this teaching and learning challenge is to explain the situation and offer coaching tips on how to manage your own learning. If you've read many 'self-help' or 'self-improvement' books, you may have noticed that the authors often start by saying that none of the existing self-help book worked very well for them. It was only after they

compiled their own list of habits or principles that they finally found the way to greatness, effectiveness, excellence, prosperity, wealth, love, power, and good digestion. Their book, they say, will save you from the time and struggle of reading any other books.

"The effectiveness of workability of any plan, however, comes from the learning struggle. Through trial and error you learn what works and what doesn't work for you. The best self-improvement comes out of real life, everyday experiences, not from books or workshops that tell you what to learn.

"Thus, my approach is to provide guidelines on how to learn good surviving, coping, and thriving skills. This is a book of useful questions and practical guidelines, it is not a book of instructions. It is a manual for discovering inborn abilities that no other human being can reveal to you. Only you can discover them. In the school of life the responsibility is on the learner, not the teacher."

*Dr. Siebert will be the Dinner speaker, Thursday evening, June 16, during the Sixth International Post-Polio and Independent Living Conference in St. Louis, MO.*

*The Survivor Personality* can be purchased for \$14.95 (p&h included) from Practical Psychology Press, P.O. Box 535, Portland, OR 97207. For credit card orders, call 800/858-9055. ■

The New York Academy of Sciences is organizing the **Post-Polio Syndrome: Advances in The Pathogenesis and Treatment** for April 27-30, 1994, at the Hyatt Regency Bethesda, One Bethesda Metro Center, Bethesda, MD 20814 (301/657-1234 or 301/657-6453 FAX). Conference registration materials are available from The Conference Department, The New York Academy of Sciences, 2 East 63rd St., New York, NY 10021 (212/838-0230, Ext. 324, or 212/838-5640 FAX). The Conference chairs are Marinos C. Dalakas, MD, National Institutes of Health, Harry Bartfeld, MD, St. Vincent's Hospital and Medical Center, New York, Leonard T. Kurland, MD, Mayo Clinic.





5100 Oakland Avenue, #206  
Saint Louis, MO 63110-1406 U.S.A.

*The month your subscription is due  
is above your name on the label.  
Renewal notices are sent to serve  
as a reminder.*

## From Our Readers

"It's impossible to realize but I'm now 72 — and except for the usual increasing weakness with ever increasing speed I don't have the other symptoms others have — pain, etc. — maybe because I have so few muscles.

"However, a big problem I've been having — and every increasing so — is elimination. My stomach muscles are almost non-existent, due to polio, and my doctor last week told me about six different laxatives which I alternate taking every day.

"He said that was the only solution and would prescribe anything to make me comfortable!!!

"Do you have any articles or magazines that might relate similar problems that you could send me?" **Larry Schneider**, 811 N. Longfellow Ave., Tucson, AZ 85711 USA

"My doctor prescribed a fiber medication for what appeared to be constipation. It aggravated the problem. He then added first one, and then a second, stool softener. They did not solve the problem. In the meantime, I had surgery to heal the damage done by straining to pass my stool. I finally made my own diagnosis of the problem, and decided that my problem was worn out muscles, and not constipation. I stopped taking the fiber, continued taking both softeners, and have had no unusual problems since."

**Dorothy Howell**, 3504 Flint St., Apt. D-118, Greensboro, NC 27405 USA

"I would like to hear from polio survivors who have able to function in spite of moderate to severe scoliosis, but who are now experiencing progressive muscle weakness resulting in much worsened scoliosis, making it quite difficult to function. I would particularly like to hear from anyone in the 60 plus age bracket who has considered, and opted, for spinal surgery." **Robert Kinney**, 4755 Sawmill Rd., Clarence, NY 14031 USA

"I have devised a method to communicate with my wife, who has a disability, from the extreme ends of our house without saying a word.

"I place a three-channel wireless intercom at her bedside; then at the other end of the house I sit next to a three-way 'touch me to light me' floor lamp.

"Whenever my wife needs my services, she puts the wireless intercom in the on position and presses the on/off voice activator several times, which in turn makes the "touch me lamp" go through the three stages of lighting up the room without anyone touching the lamp.

"It is now comfortable to be in different rooms without fear of not hearing her." **William Patapchuk**, New Jersey

The last issue of **Technical Aid to the Disabled Journal**, Ryde, New South Wales, mentions Disabled Arm Rest Toilet Support (DARTS), a removable and adjustable toilet arm rest which lets the user access the toilet from either side. Each arm swings into position indepen-

dently, giving options to users who are ambulatory or who use a wheelchair. Both arm rests can be pushed out of the way when not needed. It can be quickly attached to the toilet with anchor bolts and can easily be removed and fitted to another. The stainless steel fixture weighs 5kg and has dimensions of 560mm X 560mm. For cost and ordering information, contact **DARTS, Peter Dominguez**, 36 Trail St., Wagga, New South Wales 2650 Australia. ■

## From International Exchange of Experts and Information in Rehabilitation (IEEIR):

Monograph No. 54 "Developing Awareness of Disability in the World: Looking at Issues Relevant to Disability in Asia, the Pacific, and Africa through the eyes of U.S. Fellows" is the culmination of the 1990-93 Fellowship Program.

Application deadlines for future fellowships are February 1, 1994 and March 1, 1994. Six or seven 3-4 week-long fellowships will be awarded which must be carried out between April 1-August 1, 1994, anywhere in Asia (the Middle East), the Pacific, and Africa.

IEEIR also compiled an International Rehabilitation Resource Directory which contains over 500 rehabilitation organizations from 43 countries worldwide (U.S. not included). The directory also contains a complete listing of IEEIR fellows. It is available for \$35.

For information regarding any of the above contact: Diane E. Woods, Project Director, IEEIR c/o Institute on Disability, University of New Hampshire, Heidelberg-Harris Building, 125 Technology Dr., Durham, NH 03824 (603/862-0551, FAX 603/862-0555).