

# INTERNATIONAL POLIO NETWORK POLIO NETWORK NEWS

WINTER 1994 ♦ VOL. 10, NO. 1

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## WE CALL OURSELVES SURVIVORS

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, multiplegics, 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 superhuman 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 mind.

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 survived 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.

"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 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

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**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.**

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## WE CALL OURSELVES SURVIVORS

Continued from page 1

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-Victiming

"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 experiences. 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 books 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." ■

*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.

## International Polio Network

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314/534-0475  
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ISSN 1066-5331

*Polio Network News is an international newsletter for polio survivors, support groups, physicians, health professionals, and resource centers, to exchange information, encourage research, and promote networking among the post-polio community.*

ISSUED QUARTERLY

**EDITOR/EXECUTIVE DIRECTOR** ♦ Joan L. Headley

**SPECIAL THANKS** ♦ Margaret E. Backman, PhD,  
Vicki Johnson, RN, Joseph B. Leone, and Al Siebert, PhD

**PUBLISHER** ♦ Gazette International Networking Institute (G.I.N.I.), 5100 Oakland Ave., #206, St. Louis, MO 63110-1406 U.S.A., 314/534-0475

### ANNUAL SUBSCRIPTION:

U.S.A ♦ Individual Consumer \$12; Health Professional, Affiliated Individual, Organization, Institution \$20 (U.S. dollars only)

CANADA, MEXICO & OVERSEAS (Surface) ♦ Individual Consumer \$16; Health Professional, Affiliated Individual, Organization, Institution \$24 (U.S. dollars only)

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## **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  
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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 Incontinence	Polio History: Our Stories Must Be Told	Care and Maintenance of Your Ventilator	Understanding EMGs	Resources for the Aging Population

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

## 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

The 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, LPC, Williamsburg, VA  
Paul A. Hasak, PhD, St. Louis, MO  
Robert Ronald, SJ,  
Operation De-Handicap, Taipei, Taiwan  
Joyce A. Tepley, MSW, 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  
Deborah Given, MD,  
Riley Hospital for Children, Indianapolis, IN  
William H. Dobelle, PhD,  
The Dobelle Institute, Glen Cove, NY  
Deborah Givan, MD,  
Riley Hospital, Indianapolis, IN  
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  
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

Chuck Graham, ADA Project, Region VII,  
Columbia, MO  
Angelique Lair-Greve, PhD,  
Auburn University, Auburn AL  
Lori Hinderer, St. Louis, MO  
Margaret A. Nosek, PhD,  
Baylor College, Houston, TX  
Max J. Starkloff, Paraquad, St. Louis, MO  
Diane E. Woods, IEIIR, 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, Respironics 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 with Disability, Downey, CA

## June 18, 1994, Saturday Afternoon

Lauro S. 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 \_\_\_\_\_

**FOR OFFICE USE ONLY**

<p><b>PR</b></p> <p>C</p> <p>MO</p> <p>CC</p>	<p><b>PD</b></p>	<p><b>RD</b></p>
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**Sixth International Post-Polio and Independent Living Conference  
SESSION CHOICES**

**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 morning 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



# 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 1)

■ 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

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# A FRESH LOOK AT THE TYPE A PERSONALITY?

By Margaret E. Backman, PhD

Do people who had polio have Type A personalities? Some seem to think so, since many of those who survived polio are real strivers and doers. But why should this be important?

One reason is the common belief that overdoing it physically may in part be the cause of their post-polio symptoms, and this raises the question about how personality affects illnesses. However, before we come to any conclusions we need to understand what is meant by the Type A personality.

## WHAT IS THE TYPE A PERSONALITY?

Type A behavior is characterized by ambitiousness, aggressiveness, competitiveness, and impatience.

It has been described as the "hurry sickness." Those so classified are easily moved to anger and show frequent displays of irritation and hostility. This is in contrast to the Type B personality, which is more relaxed and more accepting of life and others.

**Research Findings** Early studies of Type A looked at the relationship of this personality syndrome to heart attacks; the implication of the findings was that a person's Type A personality caused heart attacks. That is still the idea in the popular press, even though more recent research is showing the issue to be much more complex. The results are mixed and seem to depend upon the different questionnaires and interview techniques used to assess Type A traits. It does appear, however, that certain traits, such as anger, hostility, cynicism, and suspiciousness affect a person's tendency to succumb to some illnesses.

Some researchers have also attempted to look at other illnesses, including polio. However, more research needs to be done before one can make any statements with confidence about the relationship between personality traits and polio. Although the polio literature often refers to those who survived polio as being highly successful, we must be careful that our surveys are not biased. Perhaps because of their personalities the Type A's are the ones who tend to turn up at support groups, or seek help from clinics and physicians, or willingly answer questionnaires. Thus, the Type B's may be missing from our data.

I can certainly say that in my private psychotherapy practice many survivors of polio do exhibit Type A traits, but certainly not all do so. There are also those with more "laid back" attitudes and behaviors, characteristic of the Type B personality.

Still, some hearing about the possible association between Type A and polio may worry: Did I cause my post-polio symptoms by doing too much?

**A Bad Rap** The Type A personality has been given a bad rap. It is not something to be ashamed of, nor is

it necessarily something to be changed. In some cases, it may be a very good type of personality to have, providing certain of the traits, such as hostility and anger, are kept under control. Persons with Type A are often very successful in their lives, and in terms of heart attacks do much better than their counterpart Type B's when it comes to surviving a second heart attack. Some think it is the very Type A traits that enable people to take better care of their health following the first attack. Thus, it may be a good thing that some survivors of polio have the assertiveness and energy so common to the Type A; this may be what makes them seek better medical care and be active in keeping the medical profession on its toes.

**To Conclude** So what does this mean in terms of the person who has had polio? Did the earlier efforts in treatment cause people to become Type A's? Certainly there was pressure to exercise and to be reintegrated into society at large. Yet in my clinical experience I cannot say that all those who had polio fit the classic Type A description. Yes, many lead successful lives, but many were not so fortunate. Those who were successful may have been ambitious, but not all were hostile or angry by nature.

Having polio or developing new symptoms can make one angry at times. And being frustrated by physicians who do not understand can bring out hostile feelings even in the most even tempered. But these feelings or behaviors alone do not make one a Type A. The issue is very complex as you can see.

*Labeling people may be useful in research when one is grouping large numbers of people for research studies. But labeling individuals can be misleading, inaccurate, and possibly harmful.* If people who had polio — or for that matter, MS or cancer — are made to feel that their personalities are the cause of their old or new physical problems, that is another burden put upon them, and another one that they must bear. It is this simplistic reasoning that does not help us solve the major problems associated with the post-polio syndrome.

On the other hand, our personalities and behaviors can cause us to do things that are either helpful or harmful to our health. If you understand your personality, you can make it work for you in more positive ways. ■

**MARGARET E. BACKMAN, PHD**, is a clinical psychologist in New York City who published the *Post-Polio Patient: Psychological Issues* in *Journal of Rehabilitation* (53:4 October/November/December 1987). Dr. Backman also wrote *Support Groups: Who Can Benefit?* for the Fall 1988 *Polio Network News* (Vol. 4, No. 4). For a copy of the article, send an SASE to International Polio Network. She is also the author of the book *The Psychology of the Physically Ill Patient* (Plenum Press: NY).



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## INCONTINENCE SURVEY

*Polio Network News*, (Vol. 9, No. 4), contained an incontinence survey. Below is a letter received from the researcher Vicki Johnson.

"I want to thank all of you who participated in my research by completing the survey, **Questionnaire for Survivors of Polio**. I have received well over 450 responses including many written notes and letters. I have read each of the surveys as well as the added letters, and the information obtained from this study is being compiled and analyzed at this time. I will be presenting preliminary findings of the study in Phoenix, Arizona in January 1994. In addition, I plan to be at your conference in June of 1994 presenting "Dealing with Incontinence." I will keep you informed, through the *Polio Network News* regarding future publication plans for the study.

"Although the deadline for receipt of the surveys was January 1, 1994, any of you who wish to send the surveys in are encouraged to do so. Since the data are still being compiled new surveys can be included. I will be conducting a pilot study this spring in anticipation of beginning my dissertation data collection in late spring or early summer."

### VICKI JOHNSON, R.N., M.S.N.

Texas Tech University Health Sciences Center  
School of Nursing, 3601 4th Street, Lubbock, TX 79430  
806/743-2730 or 806/795-3643

### RESOURCES:

For a copy of Urinary Incontinence, contact The American College of Obstetricians and Gynecologists, 409 12th St., SW, Washington, DC 20024-2188.

Simon Foundation, P.O. Box 815, Willmette IL 60091 (718/864-3913 or 800/23-SIMON), a support and advocacy organization for people experiencing incontinence, publishes a quarterly newsletter.

Help for Incontinent People, P.O. Box 8306, Spartanburg, South Carolina 29305 USA (803/579-7900 or 800/BLADDER) operates a Continence Referral Service (CRS).

## BRACING

*Polio Network News*, (Vol. 9, No. 3), asked readers to submit names of qualified and knowledgeable orthotists, and several were listed in the last issue. Donald S. Peters, CPO, 200 Park Ave. West, Mansfield, OH 44902

(419/522-0055 or 800/589-5026) was added by a client of his.

Also, since the last issue, we have confirmed that "the Rehabilitation Technology Department at Roosevelt Warm Springs Institute for Rehabilitation is no longer providing services through the mail. This includes repairs/modifications to braces, splints, corsets, shoes, as well as new equipment." So, consequently, once again we encourage you to send names of your bracemakers to share with other polio survivors.

Several people have asked about the status of a lighter weight brace being researched at the National Rehabilitation Hospital (NRH) as reported in the Fall 1990 *Polio Network News*. Sources at NRH tell us that the research is ongoing and has been modified to now study the "components of the brace."

## PUBLICATIONS

The proceedings of *Meeting the Challenges of Aging with a Disability: Lessons Learned from Post-Polio and Stroke* (March, 1993) are now available for \$25.00 each, plus \$3.00 shipping from L.A.R.E.I., P.O. Box 3500, Downey, CA 90242. International readers should contact L.A.R.E.I. for shipping costs.

A german translation of Charlotte LeBoeuf's *A Practical Approach to the Late Effects of Polio* is now available. Contact Dipl.-Biol. Dr. Rolf Kiessig, Polio e.V, Breiter Weg 258, 39104 Magdeburg, Germany.

*The 1994 Post-Polio Directory* is currently being updated and will be available March 1, 1994. To order, send \$3 (survivors) or \$6 (others) to G.I.N.I., 5100 Oakland Ave., #206, St. Louis, MO 63110-1406 or FAX to 314/534-5070. (Canada, Mexico, and overseas add \$1; overseas air add \$2.)

## CALENDAR

**Third Annual New Jersey State meeting**, Ocean Place Hilton, Long Branch, NJ, April 17, 1994. Contact: New Jersey Polio Network, P.O. Box 537, Martinsville, NJ 08836, or Jean Brogdon, 908/356-9447.

**Post-Polio Syndrome: Advances in the Pathogenesis and Treatment**, Hyatt Regency Bethesda, Bethesda, MD, April 27-30, 1994. Contact The New York Academy of Sciences, 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). ■