G.I.N.I. - GAZETTE INTERNATIONAL

Fifth International Polio and Independent Living Conference
St. Louis, Missouri

Wednesday, May 31, 1989, 8:30 a.m.
through
Sunday, June 4, 1989, 12:00 noon

Organized and Sponsored by
Gazette International Networking Institute (G.I.N.I.)
International Polio Network (IPN)
International Ventilator Users Network (I.V.U.N.)
4502 Maryland Avenue, St. Louis, MO 63108 U.S.A.
314/361-0475
The Board of Directors and the Planning Committee welcome you. Our goal is to provide individuals with a disability and health professionals an opportunity to share information and to solve problems. We anticipate another very special meeting typical of the previous G.I.N.I. Conferences. We are glad you are here.

**GAZETTE INTERNATIONAL NETWORKING INSTITUTE (G.I.N.I.)**

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**PLANNING COMMITTEE**

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<tr>
<th>Lawrence C. Becker, Ph.D.</th>
<th>Richard Goodwin</th>
<th>F. Howard Manning</th>
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<td>Nancy Caverly</td>
<td>Matthew Green, Ph.D.</td>
<td>Frederick Maynard, M.D.</td>
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<td>Penny Chrisler</td>
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<td>Judith Raymond Fischer</td>
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<td>Martin Wice, M.D.</td>
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<td>Oscar Schwartz, M.D.</td>
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<td>Roberta Simon, R.N.</td>
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AGENDA

Wednesday, May 31, 1989
INDEPENDENT LIVING WORLDWIDE
Ballroom, Third Floor
7:30 a.m.–8:30 a.m.
Continental Breakfast
8:30 a.m.–8:40 a.m.
Welcome
Joan Headley, B.S., M.S.
John L. Quigley, Jr., D. Min.
Jack Keane, Special Assistant to Vincent C. Schoemehl, Jr., Mayor of St. Louis

"Impact of National Policy on Independent Living: International Case Studies"
MODERATOR: John L. Quigley, Jr., D. Min.
8:40 a.m.–8:50 a.m.
"A Status Report"
Judy Heumann
8:50 a.m.–9:25 a.m.
Case 1: Disabled from Birth or Early Childhood
Trevor Boyle; Zhang Li; Adolf Ratzka, Ph.D.
9:25 a.m.–10:00 a.m.
Case 2: Disabled Later in Life
Uwe Frehse; Robert J. Ronald, S.J.; John A. Micallef
10:00 a.m.–10:30 a.m.
Break
10:30 a.m.–11:05 a.m.
Case 3: Secondary Disability
Laurie Alsop; Holger Kallehauge; Judy Heumann; Max Starkloff
11:05 a.m.–11:35 a.m.
"Overlapping Concerns: Aging, ADA, etc."
Mary Jane Owen, M.S.W.; Jim deJong; Ed Roberts
11:35 a.m.–11:45 a.m.
Closing Remarks
12:15 p.m.
Lunch

"What Really Limits Us? — Elevating Everyone's Expectations"
MODERATOR: Richard Goodwin
1:30 p.m.–2:45 p.m.
"Disability as a Social Role"
Richard Goodwin
Discussants: Speed Davis; Jim deJong; Cyndi Jones; Carol Rowse; August Rüggeberg, Ph.D.; Max Starkloff
2:45 p.m.–3:15 p.m.
Break
3:15 p.m.–4:00 p.m.
Small discussion groups
Mark Twain, Ulysses S. Grant, Robert E. Lee, Pierre Laclede
4:00 p.m.–4:45 p.m.
Summaries from discussion groups
5:00 p.m.–6:30 p.m.
DPI & Independent Living Meeting
South Lounge
6:30 p.m.
Dinner

Thursday, June 1, 1989
THE LATE EFFECTS OF POLIO
Ballroom, Third Floor
7:30 a.m.–8:30 a.m.
Continental Breakfast
8:30 a.m.–9:00 a.m.
"International Progress Reports: Networking"
Joan Headley, B.S., M.S.; Audrey King, M.A.; Rev. Robert J. Ronald, S.J.; Gertrud Weis
9:00 a.m.–10:15 a.m.
"International Progress Reports: Research"
MODERATOR: Roberta Simon, R.N.
Ruth Bell, D.N.Sc.; Carl A. Coelho, Ph.D.; D. Armin Fischer, M.D.; Raymond Roos, M.D.; Jessica Scheer, Ph.D.; Daria A. Trojan, M.D.; Anthony J. Windebank, M.D.
10:15 a.m.–10:45 a.m.
Break
10:45 a.m.–11:45 a.m.
"International Progress Reports: Research" (continued)
James C. Agre, M.D., Ph.D.; Michael Fillyaw, M.S., P.T.; Patricia Gilchrist, P.T.; Richard Owen, M.D.
12:15 p.m.
Lunch
1:30 p.m.–1:40 p.m.
"Bridging the Gap between Research & Clinical Applications"
Frederick Maynard, M.D.
1:40 p.m.–2:45 p.m.
"Prescription for Fatigue"
MODERATOR: Martin B. Wice, M.D.
Jane Dummer; Richard Owen, M.D.; William Waring, M.D.
2:45 p.m.–3:15 p.m.
Break

(continued on page 2)
AGENDA (continued from page 1)

3:15 p.m.—3:35 p.m.
"Prescription for Underventilation"
MODERATOR: Marny Eulberg, M.D.
Geoffrey T. Spencer, FFARCS

3:35 p.m.—4:45 p.m.
"Prescription for Weakness"
MODERATOR: Marny Eulberg, M.D.
James C. Agre, M.D.; Daria A. Trojan, M.D.;
Jacquelin Perry, M.D.

6:30 p.m.
Dinner

8:15 p.m.
Support Dogs for the Handicapped, Inc. –
St. Louis

Friday, June 2, 1989
THE LATE EFFECTS OF POLIO
Ballroom, Third Floor
7:30 a.m.—8:30 a.m.
Continental Breakfast

8:30 a.m.—9:40 a.m.
"Prescription for Pain"
MODERATOR: Frederick Maynard, M.D.
Thomas P. Anderson, M.D.; Ernest W. Johnson, M.D.;
Renah Shnaider

9:40 a.m.—10:00 a.m.
Break

10:00 a.m.—11:30 a.m.
"Suggestions for Exercise and Energy
Conservation"
MODERATOR: Nancy Caverly, O.T.R.
Glenn Ham-Rosebrock, C.O.; Jacquelin Perry, M.D.;
Shirley Sahrman, Ph.D., P.T.; Richard Owen, M.D.

11:30 a.m.—11:45 a.m.
"Being an Active Participant in
Your Health Care”
Dorothy Woods Smith, R.N.

"The Body AND the Mind”
Jack Genskow, Ph.D.

12:15 p.m.
Lunch

1:30 p.m.—2:30 p.m.
"Psychological Adjustment: Professional
Point of View”
MODERATOR: Stanley Yarnell, M.D.
Ruth Bell, D.N.Sc.; Laura Halstead, M.D.; Frederick
Maynard, M.D.; Renah Shnaider

2:30 p.m.—3:00 p.m.
Break

3:00 p.m.—3:30 p.m.
"Psychological Adjustment: Personal
Point of View”

3:30 p.m.—4:45 p.m.
Discussion Groups:
1 — Soulard Seminar
2 — Mark Twain
3 — South Lounge
4 — Ulysses S. Grant
5 — Robert E. Lee
6 — Eugene Field
7 — Auguste Chouteau
8 — James Eads
9 — Boulevard A
10 — Boulevard B
11 — Pierre Laclede
12 — Ballroom West
13 — Ballroom Center
14 — Ballroom East
15 — Ragtime I (Second Floor)

5:00 p.m.—6:30 p.m.
Clinic Personnel Meeting
Ulysses S. Grant

5:00 p.m.—6:30 p.m.
DPI & Independent Living Meeting
South Lounge

Friday Night in St. Louis

Saturday, June 3, 1989
ETHICAL CHALLENGES AND
SOCIAL POLICY: DISABILITY
& AGING
Ballroom, Third Floor
MODERATOR: Lawrence C. Becker, Ph.D.
Discussants: Ingolf Osterwitz, Ph.D.;
Jack Genskow, Ph.D.; August Rüggeberg, Ph.D.

8:30 a.m.—9:45 a.m.
"Ethical Theory, Medical Care, and Life and
Death Decisions”
Lawrence C. Becker, Ph.D.; Daniel Wikler, Ph.D., M.D.

9:45 a.m.—10:15 a.m.
Break

10:15 a.m.—11:45 a.m.
"Mutual Decision-Making in Life and
Death Situations”

12:15 p.m.
Lunch
**HOME MECHANICAL VENTILATION WORKSHOP**

*Boulevard A & B*

**"Summaries by the Experts"**
MODERATOR: Oscar A. Schwartz, M.D.

1:30 p.m.—1:50 p.m.
"Historical Perspectives"
Gini Laurie, Joseph Kaufert, Ph.D.

1:50 p.m.—2:00 p.m.
"Anesthesia in Severe Disability"
Geoffrey T. Spencer, FFARCS

2:00 p.m.—2:10 p.m.
"Tracheostomy Alternatives—SCI"
Susan Sortor, R.R.T.

2:10 p.m.—2:20 p.m.
"Sleep-Related Breathing Abnormalities"
Oscar A. Schwartz, M.D.

2:20 p.m.—2:30 p.m.
"The Changing Ventilation Needs of Polio Survivors"
Redento Ferranti, M.D.

2:30 p.m.—2:40 p.m.
"Swallowing Management"
Carl A. Coelho, Ph.D.

2:40 p.m.—3:00 p.m.
Questions and Answers

3:00 p.m.—4:00 p.m.
Discussion Groups
"Muscular Dystrophy – Informed Choices"
Agatha P. Colbert, M.D.

"Home Ventilator Maintenance"
Jerry Daniel, Geoffrey Waters

Robert E. Lee

"Travel with Ventilators"
Jack Genskow, Ph.D.; Adolf Ratzka, Ph.D.

"Home Ventilation in Children and Adolescents"
Allen I. Goldberg, M.D., Virginia Nelson, M.D.

South Lounge

4:00 p.m.—5:30 p.m.
"New Face Masks and CPAPs & Glossopharyngeal Breathing"
*Boulevard A & B*

MODERATOR: Augusta Alba, M.D.

Bud Blitzer; Dano S. Carbone; Pat Hanzke; Adolf Ratzka, Ph.D.; Oscar Schwartz, M.D.; Sue Sortor, R.R.T.; Geoffrey Waters

6:00 p.m.
Roman Catholic Mass
*Ragtime I, Second Floor*

6:30 p.m.
Cash Bar
*Ballroom Foyer, Third Floor*

7:30 p.m.
Banquet
*Ballroom, Third Floor*
Karen Foss, KSDK-TV, Channel 5
John L. Quigley, Jr., D. Min., President of the G.I.N.I. Board

9:30 p.m.—11:30 p.m.
Music

**Sunday, June 4, 1989**

**SPECIAL INTEREST WORKSHOPS**

7:30 a.m.—8:30 a.m.
Registration and Continental Breakfast
*Ballroom Foyer*

7:30 a.m.—8:30 a.m.
Support Group Leaders’ Meeting
*Ragtime I, Second Floor*

8:30 a.m.—9:30 a.m.
Session I

9:45 a.m.—10:45 a.m.
Session II

11:00 a.m.—12:00 a.m.
Session III

**TAMING TECHNOLOGY: OVERVIEW OF DEVICES FOR SPECIAL NEEDS**
Aimee J. Luebben, M.S., O.T.
This presentation will highlight the latest commercially available technological devices for special needs, show trends and products in the research and development stages, and discuss low cost technological options.

Sessions I, III: Ulysses S. Grant

**RECREATIONAL ADAPTATIONS**
Gordon Packer, Ph.D., P.Eng.
Slide and tape presentation of adaptive devices for recreational use.

Sessions I, III: Robert E. Lee

**TECHNOLOGY: INDEPENDENT LIVING AND WORK**
Keith Sofka
Information exchange and problem solving about technology and access to work, home, and recreation.

Session II, III: Auguste Chouteau

**SO...YOUR HOME DOESN'T FIT ANYMORE?**
Rae Duncan-Lyle
Suggestions for making your home accessible, slides of design options, working with contractors, and possible funding sources in your community. Questions wanted — there is no such thing as a silly question.

Sessions I, III: Pierre Laclede

(continued on page 4)
SPECIAL INTEREST WORKSHOPS
(continued from page 3)

VOLUNTEER SERVICE BANK
Marilyn Probe, Ed.D.
Volunteers over 60 receive state insured credit through the Missouri Division of Aging for giving respite care to persons with a disability and elderly individuals. Younger volunteers can donate their credits to someone over 60.
Session II: South Lounge

ATTENDANT CARE SCHEMES IN WEST GERMANY
Ingolf Osterwitz, Ph.D.
A presentation of the different community-based services available for individuals with a severe disability in West Germany.
Session I: South Lounge

FINANCIAL PLANNING TO PRESERVE ENTITLEMENTS
Gerald J. Zafit
Ann C. Sheehan
Financial and legal advice for persons with disabilities and their families to avoid losing government benefits.
Sessions I, II: Eugene Field

LEGAL RIGHTS AND LEGAL ISSUES
Sidney M. Wolinsky
A presentation on legal rights and issues affecting individuals with a disability and independent living such as the right to an education, airline travel, etc.
Session I: James Eads

THE SUPPORT GROUP LEADER’S ROLE AS A PEER COUNSELOR
Ingolf Osterwitz, Ph.D.
Judge Anderson, III, M.S., M.S.W.
Duane Gruis, M.S.
Techniques and strategies for helping peers cope with familiar problems.
Session III: Eugene Field

COMMUNITY RESOURCES FOR SUPPORT GROUPS: WHAT HAS (OR HAS NOT) WORKED
Roberta Simon, R.N.
Greg Larbes
Caroleanne Green
Barbara Miller
Presentations by group leaders to share their successes at using community resources to complement a support group.
Session II: Boulevard B

LIVING ALONE
Susan Armbricht
A short personal history relating management of attendants and self. Description of a support system with friends, relatives, and community services while trying not to go crazy when life falls apart.
Session II: Mark Twain

COPING SUCCESSFULLY WITH POLIO’S LATE EFFECTS
Sunny Roller
What are some common post-polio problems? What are often typical and immediate reactions to these problems? How does an individual integrate these unwelcome physical changes? These questions are sensitively discussed in the videotape, “Coping Successfully with Polio’s Late Effects,” which will be shown at this session. Participants will view the videotape and have an opportunity to share their personal responses to the tape, to their own post-polio experience, and discuss how that experience can become an opportunity to help others.
Sessions I, II: Boulevard A

LOWER EXTREMITY ANATOMICAL NEEDS VS. BRACING COMPONENTS
Glenn Ham-Rosebrock, C.O.
A discussion of the challenge of mechanically duplicating what is anatomically compromised as it relates to the individual’s needs.
Sessions II, III: James Eads

TAPPING INTO OUR HIDDEN POWER
Paul J. Rau
Restructuring the “overcome philosophy” in a self-help process which closely resembles the original alliance between young patient/physician/parents. Many polio survivors have made no changes in the overcome philosophy which was learned as children at the acute onset stage.
Session II: Ulysses S. Grant

CURRENT THESIS REPORTS ON THE LATE EFFECTS OF POLIO
Barbara R. Buchanan
“Physical, Emotional, and Social Adaptation to the Late Effects of Poliomyelitis”
Ann H. Lewis, M.N., R.N.C.
“Life Histories of Polio Survivors Residing in a Long-term Care Community: A Pilot Study”
Session I: Boulevard B

HOW TO LIVE HAPPILY EVER AFTER SANS PPS
Mari Zigmond
A video to encourage other polio people to think more carefully about nutrition. This is in no way to be contrary to the excellent care done and being done by research in the medical field.
Session III: South Lounge
FACULTY

James C. Agre, M.D., Ph.D.
Assistant Professor
University of Wisconsin Medical School
600 Highland Avenue
Madison, WI 53792

Augusta Alba, M.D.
Acting Director
Department of Rehabilitation Medicine
New York Medical Center/Goldwater Memorial Hospital
Franklin D. Roosevelt Island
New York, NY 10044

Laurie Alsop
Disability Advisory Council of Australia
Flat 1, 69A Station Street
Petersham, N.S.W. 2049
Australia

Judge Anderson, III, M.S., M.S.W.
4949 West Pine Blvd. #13D
St. Louis, MO 63108

Thomas P. Anderson, M.D.
Spaulding Rehabilitation Hospital
125 Nashua Street
Boston, MA 02114

Susan Armbrecht
15985 Nelacrest
Cleveland, OH 44112

Lawrence C. Becker, Ph.D.
Professor of Philosophy
Hollins College
Box 9641
Roanoke, VA 24020

Ruth Wilder Bell, D.N. Sc.
Assistant Professor
University of Maryland at Baltimore School of Nursing
655 W. Lombard St.
Columbia, MD 21201

Bud Blitzer
400 S. Saltair
Los Angeles, CA 90049

Trevor Boyle
Director
Physically Handicapped & Able Bodied in North Ireland
76 University Street
Belfast, BT7 1HE
Northern Ireland

Barbara Buchanan
Psychotherapist & Psychiatrist
Crisis Specialist
P.O. Box 377
Lagunitas, CA 94938

Dano S. Carbone
Porta-Lung
401 East 80th Avenue
Denver, CO 80229

Nancy Caverly, O.T.R.
Greater St. Louis Post-Polio Support Group
389 North Mosley Road
St. Louis, MO 63141

Jack Chartand
Uniglobe Action Travel, Inc.
13035 Olive Blvd. Suite 218
Creve Coeur, MO 63141

Carl A. Coelho, Ph.D.
Director
Department of Communications Disorders
Gaylord Hospital
Wallingford, CT 06492-7048

Agatha P. Colbert, M.D.
Consultant Physiatrist
Lakeville Hospital
Lakeville, MA 02346

Jerry Daniel
Ventek, Certified Home Ventilator Service
4604 Plomondo
Vancouver, WA 98661

Speed Davis
Assistant Director
Massachusetts Office on Handicapped Affairs
16 Harcourt #3J
Boston, MA 02116

Jane Dummer
205 E. Joppa #606
Baltimore, MD 21204

Rae Duncan-Lyle
Accessibility Service Coordinator
Services for Independent Living
25100 Euclid Avenue
Braeburn Building, Suite 105
Euclid, OH 44117

Marny Eulberg, M.D.
Medical Director, Post-Polio Clinic
Mercy Medical Center
1650 Fillmore
Denver, CO 80206

Redento Ferrari, M.D.
Vice President & Medical Director
Gaylord Hospital
Box 400
Wallingford, CT 06492

Michael Fillyaw, M.S., P.T.
Research Physical Therapy & Clinical Instructor
Department of Neurology
University of Vermont
305 Rowell Bldg.
Burlington, VT 05405

D. Armin Fischer, M.D.
Retired Chief, Pulmonary Service
Rancho Los Amigos Medical Center
7601 E. Imperial Highway
Downey, CA 90242

Uwe Freshe
reha-mobil GmbH
Westendstr. 93
8000 Munich 2
West Germany

Jack Genskow, Ph.D., C.R.C.
Associate Professor of Human Development Counseling
Sangamon State University
Springfield, IL 62794

Patricia Gilchrist, P.T.
Mackenzie Health Sciences Centre
Department of Physical Medicine & Rehabilitation
8440-112th Street
Room 1F1.17
Edmonton, Alberta T6G 2B7
Canada

Allen I. Goldberg, M.D., M.M., F.C.C.P.
Healthcare Consultant
1018 W. Diversey
Chicago, IL 60614

Richard A. Goodwin
Executive Director
Impact, Inc.
P.O. Box 338
2735 E. Broadway
Alton, IL 62002

Caroleanne Green
New Mexico Polio Survivors Organization
1008 Ivydale Drive
Las Cruces, NM 88005

Duane Gruis, M.S.
Independent Living Specialist
Paraquad
4475 Castleman
St. Louis, MO 63110

Lauro S. Halstead, M.D.
National Rehabilitation Hospital
102 Irving Street, NW
Washington, DC 20010-2949
Glenn Ham-Rosebrock, C.O.
Ortho Kinetics
7860 Imperial Highway, Suite F
Downey, CA 90242

Joan L. Headley, B.S., M.S.
Executive Director
International Polio Network
4502 Maryland Avenue
St. Louis, MO 63108

Judy Heumann
World Institute on Disability
1720 Oregon Street, Suite 4
Berkeley, CA 94703

Ernest Johnson, M.D.
Ohio State University College of Medicine
Room 1012, Dodd Hall
471 Dodd Drive
Columbus, OH 43210

Dr. S. Jones
Home for Handicapped (Polio) Children
LMS Compound
Trivandrum, Kerala 695 003
India

Cyndi Jones
Publisher/Editor
Mainstream
P.O. Box 370598
San Diego, CA 92137-0598

Holger Kallehauge
High Court Judge, President
National Society of Polio and Accident Victims
Tuborgvej 5
DK-2900, Hellerup
Denmark

Joseph M. Kaufert, Ph.D.
Department of Community Health Sciences
University of Manitoba
750 Bannatyne Avenue
Winnipeg, Manitoba R3E OW3
Canada

Audrey J. King, M.A.
Psychologist
Hugh MacMillen Medical Centre
350 Rumsey Road
Toronto, Ontario M4G 1R8
Canada

Greg Larbes
Ohio Polio Network
P.O. Box 32033
Columbus, OH 43232

Ann H. Lewis, M.N., R.N.C.
Instructor
Department of Nursing
Thomas Jefferson University
130 S. 9th Street, 12th Floor
Philadelphia, PA 19107

Zhang Li
Beijing Children's Welfare Institution
No. 52 Quing He
Beijing, China

Aimee J. Luebben, M.S., O.T.
Community Services
506 Freeburg Avenue
Belleville, IL 62220

Frederick Maynard, M.D.
Associate Professor of Physical Medicine & Rehabilitation
University of Michigan Medical School
1500 E. Medical Ctr. Dr., #1D204C
Ann Arbor, MI 48109-0042

Director, Art Studio, Inc.
Cleveland Metropolitan General
Highland View Hospital
Cleveland, OH 44109

John A. Micallef
Administrative Secretary
Physically Handicapped Rehabilitation Fund
Corradino, Paola
Malta

Barbara Jansen Miller
Wichita Falls Support Group
4503 Allison
Wichita Falls, TX 76308

Virginia S. Nelson, M.D.
Chief of Pediatric Medicine & Rehabilitation
University of Michigan Hospital
1500 E. Medical Center Drive, #1D204F
Box 0042
Ann Arbor, MI 48109

Ingolf Oisterwitz, Ph.D.
Avanti e.V. Hildesheim & BAG Hilfe fur Behindertk Dusseldorf
3200 Hildesheim
West Germany

Mary Jane Owen
Director
Disability Focus, Inc.
1010 Vermont, NW #1100
Washington, DC 20005

Richard Owen, M.D.
Medical Director
Sister Kenny Institute
800 E. 28th at Chicago
Minneapolis, MN 55407

Dr. Gordon Packer, Ph.D., P.Eng.
P.O. Box 232
Vauxhall, Alberta TOK 2KO
Canada

Jacquelin Perry, M.D.
Chief, Pathokinesiology/Polio Service Professor of Orthopaedics, USC
Rancho Los Amigos Medical Center
7601 E. Imperial Highway, Bldg. 304
Downey, CA 90242

Marilyn Probe, Ed.D.
Service Credit Coordinator
Grace Hill Consolidated Services
2600 Hadley St.
St. Louis, MO 63106

John L. Quigley, Jr., D. Min.
Interim Associate Minister
First Congregational Church of Webster Groves
President, G.I.N.I.
Board of Directors
9 Lenox Place
St. Louis, MO 63108

Adolf Ratzka, Ph.D.
Royal Institute of Technology
Stockholm Cooperation for Independent Living
Norrbackagatan 41
113 41 Stockholm
Sweden

Paul Rau
Greenville Post-Polio Support Group
204 Great Glen Road
Greenville, SC 29615

Ed Roberts
World Institute on Disability
1720 Oregon Street, Suite 4
Berkeley, CA 94703

Sunny Roller
Coordinator
Post-Polio Research & Training
University of Michigan Medical Center
300 N. Ingalls Bldg.
NI-2A09-0491
Ann Arbor, MI 48109

Rev. Robert J. Ronald, SJ
Operation De-Handicap
P.O. Box 7-553
Taipei, Taiwan 10098
Republic of China

Raymond Roos, M.D.
Professor of Neurology
University of Chicago Medical Center
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Information...

Registration

The registration desk is located on the third floor in the Ballroom Foyer on the rail. Participants may register on Tuesday, May 30 from 5:30 p.m. to 8:30 p.m., on Wednesday, May 31 from 7:30 a.m. to 5:30 p.m., on Thursday and Friday, June 1 & 2, from 7:30 a.m. to 2:00 p.m., Saturday, June 3 from 7:30 a.m. to 6:00 p.m., and on Sunday, June 4 from 7:30 a.m. to 8:30 a.m.

Medical Assistance

SSM Rehabilitation Institute has arranged for a physician to be on call 24 hours a day. If you need emergency medical assistance, call the hotel operator. When speaking with the operator, be sure to give your location and the phone number where you can be reached.

Procedures for Sessions

To facilitate discussion following the presentations in the Ballroom, we request that all questions be made in writing. Materials for that purpose will be located on the tables and will be collected and given to the moderator.

Some written material is provided in the Conference program. Participants are encouraged to review it in advance of the respective session. Other information will be made available during specific sessions.

No smoking will be permitted during the sessions. Smoking is permitted in the Foyer.

Messages

A message board is located in the Ballroom Foyer.

Telephone

Public telephones are located in the Ballroom Foyer next to the bar and the restrooms. The telephone at the Registration Desk is for Conference business only.

Meals

Catering has requested that we vacate the Ballroom as quickly as possible after the morning sessions so they can set up for the 12:15 p.m. lunch.

The menus for all Conference meals are posted on the message board in the Ballroom Foyer. Additional meal tickets must be purchased 48 hours in advance and may be obtained at the Registration Desk. Meal tickets must be presented to the servers.

Smoking is not permitted during meals.

Friday Night

Information concerning places to go and things to do on Friday night can be obtained at the table in front of the bar in the Ballroom Foyer. This service is provided by the Greater St. Louis Polio Support Group.

For your safety we ask that you remember that St. Louis is like any large city and that you take necessary precautions. When leaving the hotel, it is better to go in a group.

Abilities Expo-Midwest

Abilities Expo-Midwest will be held at the Cervantes Convention Center on Friday, June 2 and Saturday, June 3 from 11:00 a.m. to 6:00 p.m. and on Sunday, June 4 from 11:00 a.m. to 5:00 p.m. The Convention Center is directly across Seventh Street from the Sheraton St. Louis, but the accessible entrance is on Convention Plaza (the south side of the Convention Center). Admission is free.
Case 1

DISABLED FROM BIRTH OR EARLY CHILDHOOD.
Secondary education completed. Very intelligent with excellent grades.

Female. 18 years old. CP. Ambulatory. Used braces initially. Presently uses cane. Good use of hands. Mild spasticity. Speech difficult to understand. Attended special school for two years. Subsequent education at regular school.

Case 2

DISABLED LATER IN LIFE
Education completed.
Career stabilized.


Case 3

SECONDARY DISABILITY
Successful career.
Unaware of world of disability and availability of services.

Fall 1

BEHINDERUNG SEIT GEBURT ODER FRÜHER KINDHEIT

Höhere Schulbildung abgeschlossen.
Sehr intelligent, mit ausgezeichneten Noten

Weiblich, 18 Jahre alt. Zerebralparalyse CP! 'Spastiker'
Gehbehinderung.
Anfangs mit Gehapparat, benutzt jetzt einen Stock.
Gute Funktion der Hände. Milde spastische Lähmung.
Sprach-Behinderung, schwer verständlich!
Besuchte 2 Jahre lang eine Sonderschule.
Anschließend Ausbildung in regulärer Schule.

Fall 2

BEHINDERUNG IM SPÄTEREN LEBEN

Ausbildung abgeschlossen.
Berufliche Laufbahn stabil.

Männlich. 32 Jahre alt.
Mathematiklehrer von 15 bis 17-jährigen Schülern.
Verheiratet. Frau arbeitet als Sekretärin.
Keine Kinder.
Querschnittlähmung C5/C6 nach Autounfall.
Kürzlich aus dem Krankenhaus nach Hause entlassen.
Eigenes, zweistöckiges Wohnhaus - unzugänglich.
Ebenerdiges Schulgebäude 4 Meilen (ca. 6,4 km) von Wohnhaus entfernt.

Fall 3

SEKUNDÄRE BEHINDERUNG

Erfolgreiches Berufsleben.
Kein spezifisches Bewußtsein über "die Welt der Behinderten".
und der verfügbaren Dienstleistungen.

Männlich, 43 Jahre alt.
Verheiratet. Ehefrau arbeitet seit kurzem wieder als Krankenschwester.
Drei Kinder (20, 17, 15 Jahre alt).
Besitzt vier Automobilgeschäfte in zwei Städten.
Mit 9 Jahren Polio-Lähmung in beiden Beinen.
Beinfunktion wieder gewonnen, jedoch leichtes Hinken.
Eifriger Jogger.
Auftreten von Schmerzen, Schwäche, Müdigkeit im 42. Lebensjahr.
Falsch diagnostiziert als Landry-Guillain-Barré-Syndrom*.
Vor 3 Monaten in Polio-Klinik als Spätfolgen der Poliomyelitis diagnostiziert.
Verordnung eines Rollstuhls verursachte Depression.
Plant jetzt Ruhestand mit staatlicher Schwerbehinderten-Rente.

* aufsteigende Lähmung;
Caso primero.
Discapacitado desde el nacimiento o la niñez. Terminó la educación secundaria (el bachillerato). Muy inteligente, con notas excelentes.


Caso segundo.
Discapacitado de adulto. Terminó la educación. Tiene éxito en su carrera.


Caso tercero.
Discapacidad secundaria. Tiene éxito en su carrera. Ignorante del mundo de las discapacidades y de los servicios disponibles.

Richard Goodwin, member of the G.I.N.I. Board of Directors, is the Executive Director of IMPACT, Inc., Alton, IL. Mr. Goodwin wrote the following as part of a position paper for IMPACT.

"Disability as a Social Role"

The history of people with a disability in America has never been studied or written about in any methodical, comprehensive fashion. There have been writings published regarding specific disabilities in history, and specific approaches such as people with a disability in literature, but no comprehensive writing regarding what it means to become disabled in America has ever been published.

It is difficult to extrapolate what actually limits people with disabilities given the dearth of an historical perspective. However, the independent living movement, with which IMPACT is associated, has focused on disability as a role in society and how the expectations associated with that role are terribly restrictive, patronizing, and essentially offer little hope of living a full and productive life.

A social role simply defined is a grouping of expectations. Any role that you can think of, whether son, mother, doctor, friend, or second baseman, consists of numerous expectations. The disability role is fraught with restrictive, negative expectations which lead a person to believe that life must be miserable and extremely limiting. Some of the expectations associated with the disability role include the following:

a. the expectation that you sick,
b. the expectation that you need to be taken care of and should not live alone,
c. the expectation that you cannot work,
d. the expectation that it is in your best interest to exclude you from your age and community peers in the educational process,
e. the expectation that you do not have an inalienable human right to fully participate in your community,
f. the expectation that you will be perpetually depressed about your lot in life,
g. the expectation that your travel needs will be vastly different from the general public,
h. the expectation that you are asexual.

These expectations are reinforced by American policies and laws which provide vast amounts of funding to support keeping us in the dependent, low status, separated, un-American, archaic, patronizing disability role. The disability role is, of course, an ascribed role that we do not choose to enter. However, society makes it very difficult to break out of the disabil-

(continued on page 15)
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DISABLED passengers presently make up 5% of the traveling public in the U.S. As more services are provided, more DISABLED travelers will take advantage of them.
"What Really Limits Us?"
(continued from page 13)

ity role because often the power of American law requires that we be limited in our options. Those who do manage to rise above the disability role are thought to be brave and heroic, when in reality they are simply seeking to live a normal American life in the face of discriminatory, restrictive policies and laws.

The disability role is, of course, the logical extension of the archaic notions and prejudices which Americans have come to accept as facts regarding people with disabilities. Most Americans never interact with persons with a disability on a peer level, and are not even likely to be in the mere co-presence of persons with a disability due to the fact that historically persons with a disability have been kept out of the mainstream of American life. Even today it remains the exception for a child with a severe disability to be educated with his or her age and community peers. No wonder Americans carry with them archaic notions regarding what it means to have a disability.

Our laws, regulations, and policies essentially preclude face to face interaction between disabled and non-disabled children, and yesterday's children are today's legislators, personnel directors, teachers, and bureaucrats. It is important to highlight the fact that those of us who become disabled, and those of us who become parents of children with a disability, are fraught with the archaic notions we have tacitly accepted as fact. There is nothing more important than educating persons with disabilities and parents that a disability can be effectively managed, and people must raise their expectations as to what it is possible to accomplish as a person with a disability. Accepting society's ascribed disability role is equivalent to compliance with a life of limited options, depression, exclusion, and isolation.

People with disabilities achieve less, earn less money, have less education, more poverty, less health care, less transportation options, enjoy social/recreational activities less, are less politically active, and receive prejudicial treatment routinely. The disability role, when perpetuated at the community level results in restrictive policies and laws which limit fully integrated community participation of people with disabilities in every social context and every type of disability is affected, whether physical, mental, or sensory. Additionally, when disability occurs to an individual acceptance of the disability role as your lot in life correlates with low achievement, low self-esteem, and inability to manage and cope with life with a disability.

Promoting full community participation of people with disabilities is an issue involving social, political, social/psychological, moral, economic, and legal issues. Strategies for social inclusion of people with disabilities must effectively influence a broad spectrum of societal entities.

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Come see us at the Abilities Expo Show Booth #319.
The Late Effects of Polio: An Overview

Gini Laurie, St. Louis, MO

Polio, the dread disease of the 1950s, was virtually eliminated in the United States by the vaccines and almost forgotten except by the survivors. The majority of those survivors, with zest and determination, achieved maximum rehabilitation and lived full and productive lives in their communities. In the past several years, however, as they have grown older, some have begun to experience the late effects of polio - pain, weakness, fatigue, and sleep and breathing problems.

The Center for Disease Control estimates that there are between 200,000 and 250,000 people in the United States who have residual paralysis resulting from polio. Studies by the Mayo Clinic indicate only about 25% of the survivors may experience the late effects.

The most commonly reported symptoms of the late effects are:

- unaccustomed fatigue - either muscle fatigue or generalized body fatigue
- weakness in muscle - both those originally affected and those unaffected
- pain in muscles or joints
- sleep problems
- breathing difficulties
- swallowing problems

Unfortunately, the late effects of polio are still not well known among many physicians and they are difficult to distinguish from arthritis and other degenerative disorders of muscles, ligaments, and joints. Survivors who develop these new problems may be told "It is all in your head," given inappropriate prescriptions, or sent for expensive referrals. A frequent complaint is that their physicians do not appear to listen to them.

It is not difficult for polio survivors or physicians to become knowledgeable about the late effects. International Polio Network (IPN) through its conferences, workshops, and publications provides information and through its network of support groups provides people.

As a first step in prevention and treatment, polio survivors should undergo a general medical evaluation so one has a baseline from which to judge whether and to what extent one is experiencing the late effects. IPN, by publishing a directory of clinics and resource persons, can assist in finding an open-minded and understanding physician.

Early recognition, corrective procedures, and increased use of assistive devices can do much to alleviate pain and distress. A new brace may be needed, perhaps current crutches are damaging the arms or wrists, and a wheelchair should be used for shopping or traveling. Perhaps the arms are wearing out from propelling a manual wheelchair and a motor should be added or a change made to one of the new three-wheeled motorized chairs.

Most polio survivors have been pushing beyond their strength, trying too hard, refusing to give in or acknowledge weakness. They have been overcompensating, overachieving and, possibly, overeating.

It's time for a long, honest look at one's lifestyle. It's time to think about moderation, conservation, and common sense. Expert polio physicians at the international
polio conferences make the following recommendations:

- don't overexercie; try swimming
- don't overuse
- rest when one is tired - stop for a 15- to 30-minute rest in midafternoon
- watch weight gains
- don't smoke
- don't overindulge in alcohol
- avoid narcotics

Of course, these recommendations are not easy to follow. But they will be much easier if one has the support and understanding of other polio survivors who are facing the same changes. There are more than 250 self-help polio support groups all around the world. They are an invaluable source of information about local physicians, therapists, bracemakers, and a helping hand with adaptation to change.

One can cope with the late effects of polio by using common sense, staying informed, and sharing with other polio survivors.

---

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Advanced Health Care.
The doctors, nurses, therapists and other specialists of St. John's Mercy Rehabilitation Center are well-trained and experienced in the treatment and rehabilitation of:

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- spinal cord injury;
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- burns;
- paralyzed limbs;
- amputation;
- joint derangements;
- neurologic disorders;
- communication disorders;
- cognitive and associated behavioral disorders;
- arthritis and other types of pain;
- impaired mobility transfers or ambulation;
- hearing impairments; and
- other problems with activities of daily living.

Advanced Facilities. Our modern facilities and equipment are designed to help patients make the most of their potential, whether they're recovering from an injury or illness, or learning to cope with a disability.

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Our rehabilitation facilities include a specialized brain injury unit, as well as therapeutic swimming pool and whirlpool. We also have the only Computerized Functional Electrical Stimulation (CFES) program in St. Louis—a system that electrically stimulates paralyzed leg muscles, allowing certain individuals to pedal a special exercycle.

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Established in 1963, St. John's Mercy Rehabilitation Center was the first comprehensive inpatient rehabilitation program in St. Louis to earn accreditation from the Commission on Accreditation of Rehabilitation Facilities (CARF). CARF's certification confirms St. John's highest standards of treatment, follow-up, facilities and technical support.

It also attests to the kind of rehabilitation we believe every patient deserves—rehabilitation that helps each one reach for the most, both physically and emotionally.

St. John's Mercy Rehabilitation Center
at St. John's Mercy Medical Center
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St. Louis, Missouri 63141
(314) 569-6040

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A Member of the Sisters of Mercy Health System—St. Louis
Underventilation

Everyone's lungs change and deteriorate with age, and polio survivors, with their already limited respiratory reserve, may reach a point at which intermittent mechanical ventilation becomes necessary.

Symptoms of underventilation are:

- trunk weakness, often including scoliosis,
- loss of energy and a tendency to fall asleep easily during the day,
- general weakness and fatigue often affecting muscles not previously recognized as being weakened by polio,
- a feeling that the air in the room is in some way bad,
- claustrophobia,
- loss of mental concentration and reduced work capacity, often mistakenly attributed to lack of oxygen to the brain (treatment by oxygen therapy alone may be dangerous and can lead to acute respiratory arrest),
- sleep disturbances taking various forms, including difficulty in getting to sleep, awakening during the night with nightmares, awakening during the night feeling short of breath, waking up feeling unrefreshed or with a headache,
- frequent chest infections with difficulty in shaking off coughs or colds.

Not everyone has all the symptoms listed above, and some of the symptoms can be caused by other things, but anyone with more than 2 or 3 should be evaluated by a pulmonary specialist.

Signs of underventilation include quiet speech with fewer words per breath when speaking, difficulty in speaking for more than a short time, a reduction in breath holding time, and the obvious use of unusual muscles when breathing such as head, neck, shoulders, or arms. Cyanosis (blueness of the lips and fingernails) is a very late sign of underventilation, and this absence should not be regarded as sufficient reassurance that underventilation is not occurring.

Forced vital capacity should be measured in supine, sitting, and standing positions, and a measurement showing 400-600 ccs indicates serious underventilation. Unfortunately, in polio survivors with weak muscles and low vital capacities, formal lung function tests can be misleading. Arterial blood gas studies can often be normal during wakefulness by day, only becoming abnormal during sleep. Underventilation among polio survivors occurs primarily during sleep, and a sleep study is often helpful.

Fortunately, underventilation can be treated successfully.
What is the International Polio Network?

The International Polio Network (IPN) is the world center of information on polio and the late effects of polio. IPN was formally established in 1985 by Gazette International Networking Institute (G.I.N.I.) to link polio survivors and to coordinate post-polio support groups.

G.I.N.I. was founded in 1958 by Gini Laurie to publish an international journal, Rehabilitation Gazette, written by and for persons disabled by polio.

The Rehabilitation Gazette has always maintained a network of polio survivors. Therefore, in 1979, it was the first to recognize the increasing numbers of polio survivors reporting new symptoms of pain, fatigue, weakness, and breathing difficulties.

Today, IPN directed by Joan Headley:

- Publishes the Polio Network News, a quarterly newsletter.
- Compiles and publishes the Post-Polio Directory of 250 support groups, 60 clinics, and 100 health professionals.
- Organizes support group leaders' workshops and resources 250 support groups.
- Organizes biennial international polio and independent living conferences for polio survivors and health professionals and publishes proceedings of these conferences.
- Publishes the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors. (Available from IPN for $6.75.)

Membership in IPN is $8 a year for polio survivors and $15 for health professionals. Members receive the Polio Network News and the Post-Polio Directory.

Gazette International Networking Institute's other activities are, also, centered around "reaching, informing, and dignifying people with disabilities throughout the world." G.I.N.I. publishes the Rehabilitation Gazette, the International Ventilators Users Network newsletter, and a handbook discussing Ventilators and Muscular Dystrophy.

G.I.N.I. is a non-profit 501(3)(c) organization and donations are tax-deductible. Many friends and supporters of G.I.N.I. regularly donate to the many facets of the work of Gini Laurie and G.I.N.I.

G.I.N.I. and IPN thrive and survive on the networking of polio survivors everywhere. The information shared by one benefits all. In short, as a polio survivor, you need IPN and IPN needs you.
International Ventilator Users Network (I.V.U.N.)

A worldwide network of ventilator users and health professionals experienced in home mechanical ventilation.

Membership benefits include the biannual newsletter, IVUN NEWS.

Topics include:
- Individual Experiences
- Family Adjustment
- Equipment and Techniques
- Community Support Systems
- Education and Employment
- Travel
- Resources

Authors include:
- Health professionals
- Individuals disabled by spinal cord injury, ALS, polio, muscular dystrophy, and other neuromuscular diseases
- Parents of technology-assisted infants and children

Annual Dues: $5 for ventilator users. $15 for health professionals. ($3 extra for postage outside U.S. and Canada.)

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May 31 - June 4, 1989


$15.95 postpaid

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors edited by Laurie, Maynard, Fischer, and Raymond. A 48-page booklet in a dictionary format that contains information about the clinical problems associated with the late effects of polio based on the experiences of physicians and polio survivors.

$6.75 postpaid

Ventilators & Muscular Dystrophy by Nancy C. Schock, M.A. and Agatha P. Colbert, M.D. Discusses the availability and increasing use of mechanical ventilation for persons with Duchenne muscular dystrophy (DMD) that is changing the prognosis for the life expectancy of the disease.

$6.00 postpaid

Polio Network News & the Post-Polio Directory edited by Joan Headley. A quarterly newsletter with current information about the late effects of polio and disability-related topics. Directory lists clinics, health professionals, and support groups.

$8.00-polio survivors / $15.00-health professionals

I.V.U.N. News edited by Gini Laurie & Joan Headley. A bi-annual newsletter for ventilator assisted individuals and their families and health professionals providing a worldwide network.

$5.00-ventilator users / $15.00-health professionals

Conference Bags (sold only at the Sheraton St. Louis & the Cervantes Convention Center).

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**HOME MECHANICAL VENTILATION WORKSHOP**

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<th>Audio Cassette</th>
<th>VHS Video</th>
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<tr>
<td>Date: 6-3-89</td>
<td>Time: 3:00 - 4:00 p.m.</td>
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<tr>
<th>Tape #11</th>
<th>Home Ventilator Maintenance</th>
<th>Audio Cassette</th>
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<tr>
<td>Tape #12 - Travel With Ventilators</td>
<td>Audio Cassette</td>
<td>VHS</td>
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<tr>
<th>Tape #13 - Home Ventilation in Children &amp; Adolescents</th>
<th>Audio Cassette</th>
<th>VHS</th>
<th>1-Tape Session</th>
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<td>Date: 6-3-89</td>
<td>Time: 3:00 p.m. - 4:00 p.m.</td>
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<th>Tape #14 - Demonstrations of New Face Masks, Cpaps and Glossopharyngeal (Frog) Breathing</th>
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