SEVENTH INTERNATIONAL POST-POLIO AND INDEPENDENT LIVING CONFERENCE

St. Louis, Missouri, USA

PROGRAM

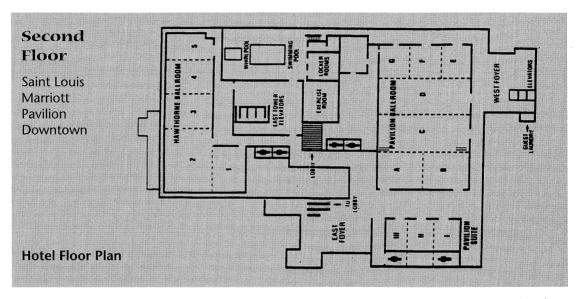
May 29-31, 1997

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

Coordinator of International Polio Network and International Ventilator Users Network

Welcome to the Seventh International Post-Polio and Independent Living Conference.

Below is a floor plan of the meeting rooms for the Conference which are located on the second floor of the West Tower of The Saint Louis Marriott Pavilion Downtown.



Please wear your name badge. It is your "ticket" for the sessions. The time schedule will be adhered to because many of the sessions will be audio and video-taped. Questions of the panelists may be submitted in writing.

Your meal tickets are in your badge holder. All meals will be served in Pavilion Salon A-D, the same room as the sessions. We must clear the room so the hotel staff can set up for the meals. Please remember to take your meal ticket with you when you leave the room. Tickets will be taken at the door(s) upon re-entry. Meal tickets may be purchased at the G.I.N.I. registration desk for the Friday luncheon by noon on Thursday and for the Saturday meals by noon on Friday.

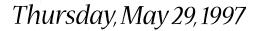
Exhibits are located in Pavilion I-I-III. (See page 9-10.)

Useful telephone numbers:

For an emergency, call 911. (If at all possible, call the hotel operator and request that they call 911 so the hotel is alerted.) BJC (Barnes-Jewish-Christian) Health System has the closest emergency room.

For scooter and equipment repair, call Ryan of Mobility Aids of Saint Louis at 997-4122.

For ventilatory equipment problems, contact the G.I.N.I. registration desk for John Blevins, of Respironics, who will be staying in the hotel.





7:30 AM - 2:00 PM REGISTRATION

7:30 - 8:20 AM CONTINENTAL BREAKFAST

All attendees welcomed

PAVILION BALLROOM A-D

8:30 am -12:00 noon The Big Picture

Moderator: Joan L. Headley

PAVILION BALLROOM A-D

Welcome

Shaaron Peters, Martin B. Wice, MD

Lessons Learned ... Future Challenges

Joan L. Headley

Transforming Experiences: Stories and Scholarship

Karen Hirsch, PhD

Target 2000: Reaching the Goal Robert A. Keegan

Polio Survivors: Data from the 1994-95 National Health Interview Survey

Linda Tompkins

10:00 - 10:30 AM BREAK

EAST FOYER

Post-Polio Motor Neurons and Units: What We Know for Sure

Neil Cashman, MD

Neil Cashman, MD

Strategies for Aging with a Disability: The Later Life Effect Study

Margaret L. Campbell, PhD

What Is Wellness? Agnes Wallbom, MD

12:00 NOON - 2:00 PM LUNCH BREAK

2:00 pm -5:00 pm

LUNCHEON

PAVILION
BALLROOM A-D

12:30 - 1:30 РМ

How Will I Support Myself?

Moderator: Linda L. Bieniek, CEAP

PAVILION BALLROOM A-D

Making Employment Decisions: The Physician's Role

Stuart J. Glassman, MD

Making Employment Decisions: Suggestions and Resources

Linda Baker Oberst and Linda L. Bieniek

3:15 - 3:45 PM BREAK

EAST FOYER

Employment Decisions: Options and Reforms within Social Security

Thomas Gloss

Medicare/Medicaid: Recent and Impending Changes

James G. Scott

Making Health Insurance Decisions
Daniel J. Ashbaker and Linda L. Bieniek

6:30 - 7:00 pm

BOOK SIGNING BY TONY GOULD

EAST FOYER

6:30 - 7:00 PM

CASH BAR

EAST FOYER

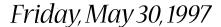
7:00 - 9:00 pm

DINNER

PAVILION BALLROOM A-D

GUEST SPEAKER: TONY GOULD, AUTHOR OF A SUMMER PLAGUE: POLIO AND ITS SURVIVORS

"Before and After Polio: Travels in Nepal"





7:30 AM - 2:00 PM REGISTRATION

7:30 - 8:20 AM CONTINENTAL BREAKFAST

All attendees welcomed

PAVILION BALLROOM A-D

8:30 am -12:00 noon How Can I Maintain Wellness?

Moderator: Jessie K.M. Easton, MD

PAVILION BALLROOM A-D

The Team Approach to Wellness for Polio Survivors

Frederick M. Maynard, MD

Team Leader: The Polio Survivor Ellen Fay Peak

Primary Care Physician's Role

Marny Eulberg, MD

The Post-Polio Specialist's Role Martin B. Wice, MD

10:00 - 10:30 AM BREAK

EAST FOYER

The Role of Activity James Agre, MD, PhD

The Role of Nutrition Lauro S. Halstead, MD

What Works: Results and Implications of Post-Polio Clinic Survey

Stanley K. Yarnell, MD

12:00 NOON - 2:00 PM LUNCH BREAK

LUNCHEON SPEAKER: JUDITH E. HEUMANN, ASSISTANT SECRETARY FOR SPECIAL EDUCATION

AND REHABILITATIVE SERVICES, UNITED STATES DEPARTMENT OF EDUCATION

12:30 - 1:30 PM PAVILION BALLROOM A-D

LUNCHEON

Session I 2:00 - 5:00 pm

How Will I Get Around?

Moderator: Beth Kowall, MS, OTR

PAVILION SALON A-C

Indicators for a Change Jacquelin Perry, MD

Professional and Personal Concerns about Bracing

Mark K. Taylor, CPO

Determining Appropriate Seating

Robbie B. Leonard, MS, PT

Surgical Options for Shoulders

Mary Ann Keenan, MD

3:15 - 3:45 PM BREAK

EAST AND WEST FOYERS

How Will I Carry Out My Daily Activities?

Similarities and Differences between Acute Poliomyelitis

Rehabilitation and Post-Polio Interventions

Paul E. Peach, MD

Physical Therapy: Not What You Remember

Marianne T. Weiss, LPT

Occupational Therapy: Not Just Reachers

Beth Kowall, MS, OTR

Rethinking the Physician/Therapist/Survivor Team

Nancy Caverly, OTR

Session II

How Do the Late Effects of

2:00 - 5:00 pm

Polio Affect Those Around Me?

Moderator: Dorothy Woods Smith, RN, PhD

From My Point of View Gail Genereau

Maintaining Relationships during Change

Lillian Genskow, RN, and Jack Genskow, PhD, CRC

Confronting Fears in Developing New Relationships

Margaret E. Backman, PhD

3:15 - 3:45 PM BREAK

EAST AND WEST FOYERS

PAVILION SALON E-F

PAVILION SALON D

Five Ways to Find Peace with One's Self and the World

Robert J. Ronald, SJ

Relationships: A Two-Way Street Joyce Tepley, LMSW/ACP, LPC

Know Your True Colors: Creative Communications

Kathleen Navarre, PhD and Angela Radlinski

Session III

2:00 - 5:00 pm

Forum on Home

Mechanical Ventilation

Moderator: Augusta Alba, MD and

Susan Sortor Leger, RRT

The Danish Experience Grethe Nyholm, RNP

The Japanese Experience: Ventilator User

Kimiyo Satoh

The Japanese Experience: Physician

Yoichi Sakakihara, MD, PhD

The American Experience: Ventilator User

Debbie Cunningham

The American Experience: Physician

Edward Oppenheimer, MD

3:30 - 3:45 PM BREAK

EAST AND WEST FOYERS

The Effects of Aging on Ventilator Equipment Choices

Augusta Alba, MD

Face Mask Displays

Session IV

Forum for Support Group

2:00 - 5:00 pm

Facilitators

Bette Plass, Bette Plass & Associates

PAVILION SALON G

Recognizing and Enhancing Leadership Style

3:30 - 3:45 PM BREAK

East and West Foyers

Utilizing New Leadership Skills



MORNING

8:30 - 9:30 am

Session A

SALON D

Post-Polio Research: What Is Being Done and Needs to be Done

Burk Jubelt, MD

Daria A. Trojan, MD

Current and proposed future research in epidemiologic, etiologic, pathophysiologic, diagnostic, and therapeutic studies will be presented.

Session B

SALON C

Isolating and Managing Pain

Ann E. Hueter, RPT Paul E. Peach, MD

The most common reasons many polio survivors experience pain and effective means of alleviation of pain symptoms will be discussed.

Session H

SALON G

West Park Hospital Post-Polio Clinical Educational Outreach and Training Program

Wendy Malisani

To help fill the need for qualified healthcare professionals to understand, assess, and treat those who experience post-polio, we developed the Post-Polio Educational Kit, a comprehensive educational tool to give knowledge and resources needed by a qualified caregiver to post-polio clients.

9:30 - 9:45 AM BREAK

EAST AND WEST FOYERS

9:45 - 10:45 am

Session C

SALON D

Fatigue: Many Causes and Possible Management

Mavis Matheson, MD

Stanley K. Yarnell, MD

In polio survivors, fatigue is more frequently multi-factorial in nature than due to a single cause, such as post-polio muscular atrophy. This presentation discusses those factors as well as the implications for management.

Session D

SALON C

Fibromyalgia and Post-Polio: Differences and Management Approaches

Anne Carrington Gawne, MD

This session will explore the diagnosis, prevention, and treatment for fibromyalgia and post-polio muscle pain.

Session Q

SALON A

Interactions with Therapists

Nancy Caverly, OTR
Beth Kowall, MS, OTR
Robbie B. Leonard, MS, PT
Marianne T. Weiss, LPT

An exchange of ideas with the OTs /PTs from the Friday session to better understand how OT/PT can assist you in your daily living.

EAST AND WEST FOYERS

BREAK

11:00 am -12:00 noon

10:45 - 11:00 AM

Session B (repeat)
SALON D

Isolating and Managing Pain

Ann E. Hueter, RPT

Paul E. Peach, MD

The most common reasons many polio survivors experience pain and effective means of alleviation of pain symptoms will be discussed.

Session C (repeat) SALON C

Fatigue: Many Causes and Possible Management

Mavis Matheson, MD

Stanley K. Yarnell, MD

In polio survivors, fatigue is more frequently multi-factorial in nature than due to a single cause, such as post-polio muscular atrophy. This presentation discusses those factors as well as the implications for management.

Session I Salon B

Applying True Colors: A Rainbow of Diversity

Kathleen Navarre, PhD

Angela Radlinski

Your individual results of the "True Color Inventory" will be used to enhance and empower your communication style and effectiveness.

12:00 - 2:00 PM LUNCH

LUNCHEON

12:30 - 1:30 РМ

PAVILION BALLROOM A-D

AFTERNOON

2:00 - 4:00 pm

The Personal Unmet Needs

Moderator: Joan L. Headley PAVILION BALLROOM A-D

and The Global

Empower Yourself by Accepting Yourself

Caroline Heckman, MA, Ed, ADTR

Unmet Needs, Evolving Solutions Liliana Bieberach and Javier Riba

What's Happening in Washington?

R. Speed Davis

Respond to Your Needs — Champion Universal Change

Cyndi Jones

MORNING

Session L

SALON B

What Works I: Neuromuscular Re-education

Diane Engelsdorfer, MA, NCTMB, NMT

A.J. Nadeau

Neuromuscular re-education — What is was like, what happened, what it is like now.

Biomagnetics Therapy

T.I. Autry

A personal view of an alternative therapy.

Session K

SALON F

What Works II: Trauma Resolution

Linda Bieniek, CEAP

Michele Marshall, MSW, LCSW

A discussion of using therapeutic approaches to work through barriers that may develop from having had polio.

Chinese Medicine

Susan Harris, Licensed Acupuncturist

Exploring ways to increase your energy (Qi) and relieve pain.

Session E

SALON A

Bracing in Depth

Glenn Ham-Rosebrock, CO Rich Stanfill, CO

Mark K. Taylor, CPO

Experienced orthotists will present additional options/ideas for bracing.

Session O

SALON E

Frogbreathing: Benefits and Techniques

Augusta Alba, MD

A video demonstrating the frogbreathing technique will be shown, followed by discussion and practice.

Session A (repeat)

Salon B

Post-Polio Research: What Is Being Done and Needs to be Done

Burk Jubelt, MD

Daria A. Trojan, MD

Current and proposed future research in epidemiologic, etiologic, pathophysiologic, diagnostic, and therapeutic studies will be presented.

Session G

SALON G

Wellness for Women with Polio: A Holistic Program Model

Rita Faudman, PhD

Sunny Roller

What is wellness? What is the wellness rsearch study af the University of Michigan investigating? How might you creat a rewarding wellness program just for you?

Session M

SALON F

Ventilators and Bi-Level Pressure Devices: What and How

Alan Fiala, PhD

Lessons learned in recognizing need for ventilator, choosing type, adapting to its use, accepting changes, insurance issues, etc..

Sarah Riley

Differences in volume and pressure products will be presented.

Oscar A. Schwartz, MD Insights into choosing ventilator products. Session N

SALON E

Assisted Cough: Benefits and Techniques

George Emerson

The setup and operation of the Emerson In-Exsufflator Cough Machine will be demonstrated.

Susan Sortor Leger, RRT A manual assisted cough technique will be demonstrated.

Steven Linder, MD, FCCP
Presentation of study on abdominal muscle functional electrical stimulation to enhance cough.

Session J SALON A

Where Will I Live?

Nancy Caverly, OTR

View a video about home accessibility. Ask questions about your home accessibility needs. Additional information will be available to take home about accessibility and other "housing" options, etc.

Session G (repeat)
SALON G

Wellness for Women with Polio: A Holistic Program Model

Rita Faudman, PhD

Sunnv Roller

What is wellness? What is the wellness rsearch study af the University of Michigan investigating? How might you creat a rewarding wellness program just for you?

Session F

SALON F

Equipment for Driving

Alan Brown

Doris Jones

A slide presentation on vehicle/van wheelchair lifts and different types of driving controls and systems followed by a discussion will be presented.

Session P

SALON E

Medical Concerns of Living Long-term with a Ventilator

Augusta Alba, MD

Oscar A. Schwartz, MD

Physicians experienced in treating individuals who use a ventilator full or part-time will offer insights about living long-term with a ventilator and will answer questions

EVENING

5:00 pm

SENATOR SUITE (1ST FLOOR)

Mass

Robert Ronald, SJ

6:30 - 7:00 pm

EAST FOYER

Cash bar

7:00 - 10:00 pm

PAVILION BALLROOM A-D

Dinner and Entertainment

Shaaron Peters, Professional Storyteller

Music by

Pieces of 8





James Agre, MD, PhD University of Wisconsin Hospital and Clinics, Madison, WI

Augusta Alba, MD Goldwater Memorial Hospital, New York, NY

Daniel J. Ashbaker O'Fallon, IL

T.J. Autry Pep, NM

Margaret E. Backman, PhD New York, NY

Linda Bieniek, CEAP Chicago, IL

Liliana Bieberach
Foundation for Equal Opportunities
Panama

Alan Brown
Mobility Systems Specialist,
United Medical, Florissant, MO

Margaret L. Campbell, PhD Rehabilitation Research and Training Center, Downey, CA

Neil Cashman, MD Montreal Neurological Institute and Hospital, Montreal, Quebec

Nancy Caverly, OTR/C Bland, MO

Deborah Cunningham Memphis Center for IL, Memphis, TN

R. Speed Davis National Council on Disability, Washington, DC

Jessie K.M. Easton, MD Sioux Falls, SD

George Emerson J.H. Emerson Company, Cambridge, MA

Diane Engelsdorfer, MA, NCTMB, NMT Vital Resource, St. Louis, MO

Marny Eulberg, MD Denver, CO

Rita Faudman, PhD University of Michigan, Ann Arbor, MI

Alan Fiala, PhD Falls Church, VA

Anne Carrington Gawne, MD Spain Rehabilitation Hospital, Birmingham, AL

Gail Generau Appleton, WI

Jack Genskow, PhD, CRC Springfield, IL

Lillian Genskow, RN Springfield, IL

Stuart J. Glassman, MD HealthSouth Rehabilitation Hospital, Concord, NH

Thomas Gloss
Special Assistant to the Associate
Commissioner for Disability,
Social Security Administration,
Baltimore, MD

Tony Gould London, England Lauro S. Halstead, MD National Rehabilitation Hospital, Washington, DC

Glenn Ham-Rosebrock, CO Orthokinetics, Downey, CA

Susan Harris Licensed Acupuncturist

St. Louis, MO

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Caroline Heckman, MA, Ed, ADTR
Masters and Johnson Institute,

Judith E. Heumann
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Ann E. Hueter, RPT Denver, CO

Cyndi Jones Publisher, *Mainstream*, San Diego, CA

Doris Jones Greater St. Louis Post-Polio Support Group, St. Louis, MO

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Beth Kowall, MS, OTR Greenfield, WI

Susan Sortor Leger, RRT Respironics, Inc., Lyon, France

Robbie B. Leonard, MS, PT Medical University of South Carolina, Easley, SC

Steven Linder, MD, FCCP VA Medical Center, Palo Alto, CA

Wendy Malisani West Park Hospital, Toronto, Ontario

Michele Marshall, MSW, LCSW Masters and Johnson Institute, St. Louis, MO

Mavis J. Matheson, MD Regina, Saskatchewan, Canada

Frederick M. Maynard, MD MetroHealth Center for Rehabilitation, Cleveland, OH

A.J. Nadeau Hazelwood, MO

Kathleen Navarre, PhD Assistant Professor, Delta College, University Center, MI

Grethe Nyholm, RNP Center for Home Ventilation, Copenhagen, Denmark

Linda Baker Oberst Missouri Governor's Council on Disability, St. Louis, MO

Edward A. Oppenheimer, MD S. California Permanente Medical Group, Los Angeles, CA Paul E. Peach, MD Roosevelt Warm Springs Institute, Warm Springs, GA

Ellen Fay Peak Birmingham, AL

Jacquelin Perry, MD Rancho Los Amigos Medical Center, Downey, CA

Shaaron Peters
Professional Storyteller, St. Louis, MO

Bette Plass Bette Plass & Associates, Mount Prospect, IL

Angela Radlinski Director of Student Activites, Delta College, University Center, MI

Javier E. Riba Foundation for Equal Opportunities Panama

Sarah Riley Respironics, Westminster, CO

Sunny Roller
University of Michigan Medical Center,
Ann Arbor, MI

Robert Ronald, SJ Operation De-Handicap, Taiwan

Yoichi Sakakihara University of Tokyo, Tokyo, Japan

Kimiyo Satoh Japanese Ventilator Users Network, Sapporo City, Japan

Oscar A. Schwartz, MD, FCCP St. Louis, MO

James G. Scott HCFA Region VII, Kansas City, MO

Rich Stanfill, CO Advanced Orthotics and Prosthetics, St. Louis, MO

Mark K. Taylor, CPO University of Michigan Orthotics & Prosthetics Center, Ann Arbor, MI

Joyce Ann Tepley, LMSW/ACP, LPC Dallas, TX

Linda Tompkins National Center for Health Statistics, Hyattsville, MD

Daria A. Trojan, MD, MSc Montreal Neurological Institute and Hospital, Montreal, Quebec

Agnes Wallbom, MD University of Michigan Medical Center, Ann Arbor, MI

Martin B. Wice, MD St. John's Mercy Medical Center, St. Louis, MO

Marianne T. Weiss, LPT University of Indianapolis, Indianapolis, IN

Dorothy Woods Smith, RN, PhD University of Southern Maine School of Nursing, Portland, ME

Stanley K. Yarnell, MD St. Mary's Hospital/Stanford University, San Francisco, CA

Visit the exhibits in Pavilion I-II-III

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Body Wise International/Independent Consultants

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Products: Nutritional and Antioxidant Supplementation

J.H. Emerson Company

CAMBRIDGE, MASSACHUSETTS

Products: Non-invasive negative pressure chest respirator, and the In-Exsufflator Cough Machine, for the removal of secretions in individuals with an ineffective cough.

Respironics, Inc./Porta-Lung

Murrysville, Pennsylvania/Denver, Colorado

Products: BiPAP® S/T Ventilatory Support System, PLV®-100 Portable Ventilator, and the NEV®-100 Negative Pressure Ventilator

Respironics' BiPAP S/T Ventilatory Support System is a mask-applied, pressure support ventilator designed specifically for home use. The BiPAP System cycles in response to a patient's respiratory flow and compensates for most leaks, making it an effective and less complicated alternative to conventional home ventilators.

The LIFECARE PLV-100 Portable Ventilator is a microprocessor-controlled, electrically-powered, volume ventilator that may also be pressure limited. It is patient or time-cycled and is specifically designed for long-term use in the home. Its' small size and light weight make it suitable for transport applications.

The LIFECARE NEV-100 is a microprocessor-controlled, electrically-powered noninvasive negative pressure ventilator that combines state-of-the-art technology with simple controls. The NEV-100 may be patient or time-cycled and can be used with a variety of applications devices, including Soft Seal Chest Shells, Nu-Mo® Garments, and the Porta-Lung™ Portable Ventilating Chamber. All application devices are available in a variety of sizes to fit a wide range of patients.

BiPAP Systems are the subject of U.S. Patents #5148802, #5239995, #5313937, #5433193, #2,024,477, #EP0425092, #69021681.5-08, and other pending U.S. and foreign patents. BiPAP, PLV-100, NEV-100, and Nu-Mo are trademarks of Respironics, Inc.

Post-Polio Syndrome: A New Challenge for the Survivors of Polio

Visit Pavilion I-II-II and try out *Post-Polio Syndrome: A New Challenge for the Survivors of Polio,* a new CD-ROM created by BioScience Communications, a division of Edelman Healthcare Worldwide, supported by an unrestricted educational grant from ICN Pharmaceuticals.

Sign up for a free copy, which will be available later this summer.

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MEDICARE SUPPLEMENT

for the Social Security Disabled

Call 1-800/750-5222 organization concerned with the issues of people with physical disabilities. It is dedicated to supporting the independent living, self-direction, dignity, and personal achievement of people everywhere with disabilities. Its activities are financed by subscription receipts and donations from diverse sources.

G.I.N.I. continues its historic educational and advocacy efforts related to poliomyelitis and late effects of poliomyelitis through the International Polio Network (I.P.N.). Building on this history, G.I.N.I. also continues its work with respiratory polio survivors, expanding its role to other ventilator users through the International Ventilator Users Network (I.V.U.N.).

G.I.N.I. is international in scope and collaborative in style. G.I.N.I. operates in two modes: information gathering and dissemination, and connecting people with people.

G.I.N.I. is a compiler and source of information ...

- It reviews and evaluates information.
- It publishes substantive newsletters, journals, and educational materials.
- It maintains an historic, yet up-to-date, library and resource center, particularly regarding poliomyelitis and its late effects, independent living, and ventilators.
- It provides detailed responses to specific inquiries on request.

G.I.N.I. is a network of people ...

- It acts as a resource for the establishment and promotion of polio and other self-help groups in the United States and around the world.
- It encourages and supports local, community-based organizations dedicated to education in disability issues and improvement in the delivery of health care services for people with disabilities.
- Through its publications and by organizing periodic international conferences, it gathers together
 people with disabilities, leaders in the disability rights movement, health care professionals, and
 interested family and friends to interact, to learn from each other, and to define current disabilityrelated issues.

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Coordinator of International Polio Network and

International Ventilator Users Network

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