



**SIXTH INTERNATIONAL**

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**Post-Polio and  
Independent Living  
Conference**

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

Welcome to St. Louis and this unique gathering, the Sixth International Post-Polio and Independent Living Conference. Five previous conferences, coordinated by G.I.N.I. (1981, 1983, 1985, 1987, 1989) can be credited with bringing disability and post-polio issues to the attention of the general public and the medical community. G.I.N.I. conferences are noteworthy for their camaraderie and for their ripple effects all over the globe. The list of individuals and organizations who got their start at a G.I.N.I. meeting is too long to enumerate.

Our goal is to provide a forum that will cause you to think, offer an opportunity for interaction, and answer your questions. We want you to leave with a feeling not only of having received, but also of having participated.

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

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# PROGRAM OVERVIEW

FINAL PROGRAM

**JUNE 15, 1994**

## Wednesday Evening

3:30-5:30 pm  
Registration

**JUNE 16, 1994**

## Thursday Morning

8:30 am - 1:30 pm  
Registration & Coffee

9:30-11:30 am  
Pavilion Ballroom, Salon C-D  
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  
Pavilion Ballroom, Salon C-D  
Status of Polio in the  
World Today  
Defining Post-Polio  
Problems  
Incidence and Prevalence  
of Post-Polio Problems

3:30-5:00 pm  
Pavilion Ballroom, Salon C-D  
Coordinating Post-Polio  
Treatment: You, Your  
Primary Physician and  
Your Expectations  
The Battle with Bracing

## Thursday Evening

6:30 pm • DINNER  
Pavilion Ballroom, Salon C-D

*Why Survivors Survive*  
Al Siebert, PhD

**JUNE 17, 1994**

## Friday Morning

7:30-8:30 am • Registration  
& Continental Breakfast

8:30-9:45 am  
Pavilion Ballroom, Salon C-D  
Post-Polio Corrective  
Surgery: Then and Now  
Recovery from  
Orthopedic Injury

10:15-11:30 am  
Pavilion Ballroom, Salon C-D  
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

12:30-1:30 pm • Registration

1:30-5:00 pm  
Pavilion Ballroom, Salon C  
**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

## 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>
Salon C	Salon F	Pavilion Suite I
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  
Pavilion Ballroom, Salon D  
**SESSION II • Disability in Perspective**

1:30-5:00 pm  
Living With Disability:  
Perspectives

1:30-3:00 pm  
Disability as a Life Course:  
The Theory and Research  
Differentiating Post-Polio  
from Aging  
Effects of Non-Polio  
Health Problems  
Implications of Early Experiences

3:30-5:00 pm  
Living with Disability:  
What Works?

# THE SIXTH INTERNATIONAL POST-POLIO & INDEPENDENT LIVING CONFERENCE

**JUNE 18, 1994**

Continental Breakfast

<b>SESSION D</b> Salon D Dealing with Chronic Pain	<b>SESSION E</b> Salon G Other Therapies for Post- Polio	<b>SESSION F</b> Pavilion Suite III Post-Polio Clinics: Goals and Approaches	<b>SESSION G</b> Fort San Carlos I Dealing with Inconti- nence	<b>SESSION H</b> Salon E Polio History: Our Stories Must Be Told	<b>SESSION I</b> Consul Room The Ventilator: Technical and Trach Talk	<b>SESSION J</b> Fort San Carlos II Under- standing EMGs	<b>SESSION K</b> Pavilion Suite II Resource Exchange
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1:30-5:00 pm  
Pavilion Suite I

**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**

3:30-5:00 pm

**Diaphragmatic Pacer:  
What, Who, and When**

**Living at Home:  
Overcoming Obstacles**

1:30-5:00 pm  
Pavilion Ballroom, Salon E-G

**SESSION IV • Forum for  
Post-Polio Coordinators**

Networking G.I.N.I. Style

**What, How, and Why's  
of Facilitating**

## Saturday Afternoon

12:30-1:30 pm • Registration

1:30-3:10 pm

Pavilion Ballroom, Salon C-D

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

3:30-5:00 pm

Pavilion Ballroom, Salon C-D

**Health Care Reform: Its Impact  
on People with Disabilities**

**Health Care Reform: Caveats  
from International Participants**

## Saturday Evening

7:00 pm • DINNER AND MUSIC

Pavilion Ballroom, Salon C-D

**A Celebration with Friends**

Judith E. Heumann, Assistant Secretary  
for Special Education and  
Rehabilitative Services, United States  
Department of Education.

**JUNE 19, 1994**

## Sunday Morning

9:30 am • BRUNCH

## Thursday Morning ■ June 16, 1994

9:30 — 11:30 am ■ Pavilion Ballroom Salon C-D

### ***G.I.N.I. Then and Now***

JOAN L. HEADLEY

Gazette International Networking Institute (G.I.N.I.) is named for its founder, Gini Laurie, who died in 1989. For over 30 years, Gini advocated for people with disabilities, especially her polio survivor friends from the Toomey Pavilion respiratory ward in Cleveland, Ohio, where she volunteered during the polio epidemics of the 1950s. Her love for people, information, and the sharing of that information led from an informal mimeographed newsletter to the *Rehabilitation Gazette*, a respected journal by and for people with disabilities.

In 1979 Gini published a letter in the *Gazette* from a polio survivor regarding new health problems. The ensuing reaction motivated Gini to instigate a conference "Whatever Happened to the Polio Patient?" in Chicago in 1981. Another post-polio meeting was held in Oakland later that year. These two conferences served to reunite and connect polio survivors with each other and with health professionals, carrying the message that there were post-polio problems needing to be addressed. The cause was furthered by medical conferences at Warm Springs in 1984 and 1986. Subsequent G.I.N.I. conferences were held in 1983, 1985, 1987, and 1989. Augmented over the years by the International Polio Network, under the G.I.N.I. umbrella, the search for answers continues on many fronts as evidenced by the program of this conference.

Gini, her husband Joe, their friends, and their work were featured on CBS "Sunday Morning" in 1983 and again in 1986. We present this video as a way for you to remember, or to meet, Gini Laurie.

### ***Post-Polio Syndrome 101: Acute Polio and Post-Polio Theories***

FREDERICK M. MAYNARD, MD; MARTIN B. WICE, MD; AND STANLEY K. YARNELL, MD

Poliomyelitis, or infantile paralysis, is caused by a virus which destroys or damages certain nerve cells in the central nervous system. To understand post-polio problems it is important to understand the original polio infection and its effects. Polio survivors are facing new weakness. What is triggering or hastening this process? Aging? General health? Stress? Orthopedic problems? Overuse? Immunological response?

## Thursday Afternoon ■ June 16, 1994

1:30 — 3:00 pm ■ Pavilion Ballroom Salon C-D

### ***Status of Polio in the World Today***

ROBERT A. KEEGAN, CENTERS FOR DISEASE CONTROL AND PREVENTION

Before post-polio issues are addressed, it is incumbent upon us to explore the incidence of acute cases of poliomyelitis throughout the world: Who gets polio in the '90s, why, and what needs to be done to eliminate polio from the world and ultimately eliminate post-polio issues?

## **Defining Post-Polio Problems**

NEIL R. CASHMAN, MD; LAURO S. HALSTEAD, MD; FREDERICK M. MAYNARD, MD;  
JACQUELIN PERRY, MD;

Several terms are used to label the problems facing polio survivors: delayed effects of poliomyelitis, post-poliomyelitis muscular atrophy, post-polio syndrome, the late effects of polio, post-polio sequelae, progressive post-polio muscular atrophy, progressive muscular atrophy, post-polio muscular atrophy syndrome, and post-poliomyelitis syndrome. Why are there so many terms? Are they all describing the same condition? Is it important to establish specific definitions? How does confusion over terminology impact health professional/survivor relationships?

## **Incidence and Prevalence of Post-Polio Problems**

P. ELLEN PARSONS, PHD, MPH; JONATHAN M. RAMLOW, PHD, MPH

The post-polio literature, including lay and the popular press, cites percentages of individuals experiencing post-polio problems between 18 and 65%. Why is the range so great? What do the epidemiological studies report? Are these studies adequate? Is there a need for further study? Is it important to establish a specific percentage? How does confusion over the percentage impact the health professional/survivor relationships?

**3:30 — 5:00 pm ■ Pavilion Ballroom Salon C-D**

### **Coordinating Post-Polio Treatment: You, Your Primary Physician and Your Expectations**

MARNY EULBERG, MD; DOROTHY WOODS SMITH, PHD, RN; STANLEY K. YARNELL, MD

This panel will offer perspectives on bringing new information and ideas into an individual's life and health care plan. Finding a balance between being entirely on one's own and feeling at the mercy of the health care team is not always easy. Two physicians and a nurse, all health professionals with acquired disabilities, will offer ideas on how to be realistic about expectations of health care professionals, and how to be actively involved in deciding what tests, treatments, or lifestyle modifications might be helpful.

### **The Battle with Bracing**

ARMAND ZILIOLI, MD, MODERATOR; ALBERT ESQUENAZI, MD; JOHN R. FISK, MD;  
GLENN HAM-ROSEBROCK, CO

On one hand, there are polio survivors who won their original battle with braces by throwing them away, and today some are in need of new bracing. Survivors who have worn braces for years now are faced with worn out metal and leather. On the other hand, orthotists who built and repaired braces for survivors during the epidemics have retired, and the younger orthotists are eager to create new, modern replacements for antique solutions. Can polio survivors and orthotists work hand in hand?

**Thursday Evening ■ June 16, 1994**

**6:30 pm ■ DINNER & SPEAKER ■ Pavilion Ballroom Salon C-D**

### **Why Survivors Survive**

AL SIEBERT, PHD

Dr. Al Siebert is nationally recognized for his survivor personality research and is author of *The Survivor Personality*.

## Friday Morning ■ June 17, 1994

8:30 — 9:45 am ■ Pavilion Ballroom Salon C-D

### ***Post-Polio Corrective Surgery: Then and Now Recovery From Orthopedic Injury***

NICKIE LANCASTER, RN, MODERATOR; MARY ANN KEENAN, MD; JACQUELIN PERRY, MD;  
IRWIN M. SIEGEL, MD; ENSOR E. TRANSFELDT, MD; SUNNY ROLLER, MA

Polio surgeries to reposturize young polio survivors to enable mechanical function to be restored were, in many cases over decades, experimental but effective. Surgeries for mechanical corrections of aging post-polio survivors, or any surgeries for any reasons on mature post-polio survivors, have varying results and slower recovery time due, in part, to the effects of new mechanical weakness, anesthesia, and rehab exercise limitations. What are realistic expectations following surgery for polio survivors today? How must we re-educate the medical team prior to surgery to insure desirable post-op results?

10:15 — 11:30 am ■ Pavilion Ballroom Salon C-D

### ***Facing Surgery When Breathing Is A Problem New Breathing Problems In Aging Polio Survivors New Swallowing Problems In Aging Polio Survivors***

KATHLEEN A. NAVARRE, PhD, MODERATOR; AUGUSTA S. ALBA, MD; CARL A. COELHO, PhD;  
ANN ROMAKER, MD; OSCAR A SCHWARTZ, MD

This session will begin with the demystifying of fears surrounding surgery when breathing is a problem. Medical professionals will then discuss the symptoms, tests, and management of breathing problems in polio survivors. Information from a four-year follow up on individuals with swallowing problems will also be presented.

## Friday Afternoon ■ June 17, 1994

### **Session I (Salon C) Energy Conservation and Lifestyle Enhancement**

1:30 — 3:00 pm

NANCY CAVERLY, OTR, MODERATOR

#### ***Finding Your Personal Threshold***

MARTIN B. WICE, MD

#### ***Determining Prescribed Activity***

RUBIN FELDMAN, MD

Determining the presence of muscle fatigue during exercise and scheduling of exercise, along with the importance of planning events and utilizing a daily rest period will be discussed.

LAURO S. HALSTEAD, MD

National Rehabilitation Hospital Post-Polio Clinic has developed a limb classification for prescribing exercise in a clinical study. Definitions, results of a prospective study, and guidelines for use in a clinical setting, will be briefly discussed.

GREG NEMUNAITIS, MD

This talk will review the bioengineering principles of hydrotherapy that will support an exercise plan for the improvement of the flexibility and the cardiovascular fitness of the post-polio survivor.

MARIANNE T. WEISS, LPT

Suggestions will be provided on how to engage in basic activities of daily living without causing harm to the body. The concepts of wisdom of movement and economy of movement will be discussed. Examples of activities involving standing, sitting, and lying down will be included.

ANN E. HUETER, RPT

Suggestions for relatively inexpensive equipment and techniques to be used at home for increasing and maintaining flexibility and cardiovascular fitness.

**3:30 — 5:00 pm**

### ***Choosing Correct Equipment***

ROBERT B. McCOWN, PhD

Virtual reality, high-tech hype, adaptive equipment, and low-tech solutions: you don't need a fortune to control your environment.

GRACE R. YOUNG, OTR

Will offer energy-saving ideas incorporating environmental adaptations, adaptive equipment, and work simplification.

### ***Adapting to Using Adaptive Equipment***

SUNNY ROLLER, MA

"What is this new hardware?! I'm not sure I'm ready for this. The doctor tells me I need to use this equipment, but it feels like a painful regression." This presentation provides inside information on how to focus on real priorities and pace adaptive lifestyle changes.

### ***Ideas for Relaxing***

HANNAH HEDRICK, PhD

T'ai chi and yoga will be introduced as ideas for energy balancing.

## **Session II (Salon D)**

### **Living With Disability: Perspectives**

**1:30 — 3:00 pm**

LINDA BIENIEK, CEAP, MODERATOR

#### ***Approaching Disability as a Life Course: The Theory***

JESSICA SCHEER, PhD

#### ***Reviewing the Research on Disability as a Life Course Perspective: Post-Polio Studies***

MARGARET L. CAMPBELL, PhD

Results from 120 polio survivors in a five-year Comparative Study of Aging and Disability will be used to demonstrate the effect of the timing of acute onset of polio on severity of initial impairment, presence or absence of post-polio syndrome, and psychological well-being and adjustment to disability at time of measurement in 1990 to 1992.

## ***Differentiating Post-Polio from Aging***

STEVEN P. DINSMORE, DO

## ***Recognizing the Effects of Non-Polio Health Problems on Post-Polio Symptoms***

FREDERICK M. MAYNARD, MD

## ***Understanding the Implications of Early Experiences on Later Coping Responses***

MARY WESTBROOK, PHD

A five-year study of 176 post-polio survivors collected accounts of early memories and their reactions to post-polio. Conclusions as well as suggested strategies for coping will be discussed.

**3:30 — 5:00 pm**

### ***Living With Disability: What Works?***

This panel will focus on what helps to make living with disabilities easier, more energetic, fulfilling, satisfying, productive, and enjoyable.

### ***Responding to Losses: A Practical Framework***

JACK GENSKOW, PHD, CRC

### ***Revising Expectations: The Effects of Perception on Our Experiences of Disability***

THOMAS HALE, EdS, LPC

### ***Managing Your Needs in Relationships***

MARGARET E. BACKMAN, PHD

### ***Strengthening Our Spirituality***

ROBERT RONALD, SJ

### ***Adjusting Our Attitudes: Ten Axioms for Living with Disabilities***

JOYCE A. TEPLEY, MSW/ACP, LPC

### ***Expanding Our Energy Spheres and Sources***

LINDA BIENIEK, CEAP



## **Session III (Pavilion Suite I) Forum for Ventilator Users**

**1:30 — 3:00 pm**

AUGUSTA S. ALBA, MD, MODERATOR

### ***Improving Cough and Decreasing Infection***

SUE SORTOR LEGER, RRT; JOHN R. BACH, MD

Ventilator users frequently fight infections. This session will present suggestions to decrease infection, including the importance of coughing.

### ***Changing Equipment as Diagnoses Change***

DEBORAH C. GIVAN, MD

This discussion will deal with the nasal ventilation of children with neuromuscular disease and the subsequent adaptation of this technique to ventilate a child with congenital central hypoventilation syndrome (CCHS). I will discuss the risks, benefits, and pitfalls of using this therapy, and the safeguards we have implemented for this particular situation.

DANIEL M. GOODENBERGER, MD

Changing from no support to non-invasive support to tracheostomy ventilation, and the indications for those decisions, including troubleshooting and a brief discussion of ventilator speech.

JOSEPH VIROSLAV, MD

Respiratory failure is common in patients with neuromuscular diseases and spinal cord injuries. Ventilation of these patients without a tracheostomy is effective in improving exercise tolerance as well as preventing hospitalization.

**3:30 — 5:00 pm**

MICKIE MCGRAW, MODERATOR

### ***Diaphragmatic Pacer: What, Who, and When***

WILLIAM H. DOBELLE, PhD

Two hundred cases with a new breathing pacemaker have dispelled many myths and misunderstanding about diaphragm pacing. This equipment permits 24-hour breathing in quadriplegics without a tracheostomy.

### ***Living at Home: Overcoming Obstacles***

EDWARD A. OPPENHEIMER, MD

The ideal process will be compared to what often occurs. The discussion will include: medical and psycho-social evaluation (including resource evaluation); informed choice; the role of family members in decision making and caregiving; advanced decision making and setting limits; and paid caregivers. Comments will reflect the perspective of a pulmonary physician, as well as a care coordinator in a large group-practice managed care setting.

GEORGE B. MALLORY, JR., MD

In addition to an overview of pediatric home mechanical ventilation, medical issues such as the ventilator, infection, growth and development, as well as financial, family, academic, and ethical issues will be discussed.

PATRICK LEGER, MD

Based on extensive experience in the field of non-tracheostomy ventilation, specifically nasal mask ventilation, and experience with using long-term tracheostomy ventilation in the home setting, this presentation will describe solutions implemented in France for overcoming obstacles to living at home.

## **Session IV (Salon E-G) Forum for Post-Polio Coordinators**

**1:30 — 5:00 pm**

### ***Networking G.I.N.I. Style***

JOAN L. HEADLEY

A network is different from an organization. This presentation will highlight the process of networking, some misconceptions regarding networking, and the many benefits.

### ***What, How, and Whys of Facilitating***

ELIZABETH PURCELL

This workshop is designed for those who already have the pleasure of facilitating groups or who are aspiring to be a facilitator. In a three-hour period we will develop facilitation skills which will enhance your support group meeting. The training will address personal communications, developing a focus and mission for a support group, and finally, facilitating successful group interaction. The process for the day will include plenty of small group interacting to practice skills and to meet other support group coordinators from around the world. The afternoon will conclude with an opportunity to share and celebrate your expertise with your fellow coordinators.

**Saturday Morning ■ June 18, 1994**

**9:00 — 10:00 am ■ Sessions A-K**

**10:30 — 11:30 am ■ Continuation of Sessions A, C, D; repeat of all others**

## **Session A (Salon C) Challenges Facing Individuals with Disabilities**

WILLIAM R. GREENE, EdD, MODERATOR

DIANE E. WOODS

The challenges facing individuals with disabilities vary around the globe. A more global point of view will be presented by the project director of International Exchange of Experts and Information in Rehabilitation (IEEIR).

ANGIE LAIR-GREVE, PhD

The concepts of strength in numbers and a shared disability culture, core values of the independent living philosophy, are reinforced by a cross-disability focus. While these are laudable values and worthy goals, in some instances they may continue to marginalize certain groups while thrusting others into roles where they find themselves "speaking up for the rights of others," a charge we have often leveled at the able-bodied. Perhaps it is time we reexamine what we mean by cross-disability and evaluate how we have operationalized the concept.

LORI HINDERER

There are 43 million people with disabilities in America, all with varying degrees of involvement, and all with very diverse needs. However, while the ideals of the independent living movement encompass all people with disabilities, it is important to recognize that agendas may differ among those with different disabilities. One such group consists of those with progressive, often chronic diseases such as cancer, AIDS, or certain forms of neuromuscular disorders. Diseases impose emotional as well as physical changes, many times limiting one's focus to fighting for one's life. Therefore, understanding the implications of the difference between having a disability and having a disease is essential.

MAX J. STARKLOFF

This presentation will briefly discuss the challenges facing individuals with disabilities, and how the independent living movement can prepare to meet those challenges.

SANDY CLUSTER

A polio survivor will relate a positive experience with Missouri's personal assistance program which is consumer controlled and state funded.

DUANE GRUIS

Missouri's personal assistance program is important to its citizens with disabilities in assisting them live to independently.

CHUCK GRAHAM

This presentation will be an update on implementation of the Americans With Disabilities Act and the role of people with disabilities in this effort.

## **Session B (Salon F) Update on Social Security**

J. KENNETH MCGILL

The session will focus on Social Security benefits available to people with disabilities, the application and evaluation process, and linkages to rehabilitation, work incentives, and employment initiatives. Of special interest will be a major "reengineering" of the disability claims process.

DOUGLAS M. SMITH

This presentation will provide the perspective of a lawyer who publishes books on disability. The roles of the claimant and the physician in a claim for Social Security disability will be discussed, as well as how "reengineering" might change those roles.

## **Session C (Pavilion Suite I) Face Masks Show and Tell and Frogbreathing Lessons**

AUGUSTA S. ALBA, MD; SUSAN ARMBRECHT; JOHN R. BACH, MD; JEFF DAVIS, RRT;  
SHELLEY MORRIS-TOMAZCVIC, RRT; NANCY NICOLL; VERA OVERHOLT; WILMA PIERCE, RRT;  
LENNART REMMER, MFT; OSCAR A SCHWARTZ, MD

The increase in the use of non-invasive intermittent positive pressure ventilation (NIPPV), and continuous positive airway pressure (CPAP) has also accelerated the search for "a better face mask." This session will provide an opportunity for ventilator users, health professionals, and manufacturers to demonstrate oral and nasal masks.

Frogbreathing, or glossopharyngeal breathing (GPB), "involves the use of the tongue and pharyngeal muscles to add to an inspiratory effort by projecting boluses of air past the glottis." This technique will be demonstrated.

## **Session D (Salon D)**

### **Dealing with Chronic Pain**

RICHARD T. KATZ, MD; KATHERINE E. MITCHELL; KENNETH RUSS, PhD; DOROTHY WOODS SMITH, RN, PhD;  
MARIANNE WEISS, LPT

*The Late Effects of Polio — An Overview* recommends that polio survivors avoid the use of painkillers, especially narcotics. Pain is a warning signal from the body and, for many survivors, the pain is warning of overuse. Painkillers cover up the pain, resulting in more overdoing.

Many survivors report success in managing pain by managing fatigue, i.e., resting, pacing, and not overdoing. However, for some survivors the struggle with pain continues. This session will provide a discussion of chronic pain from the point of view of a survivor with suggestions offered by a physiatrist and a physical therapist, along with information regarding biofeedback, the Alexander Technique, and therapeutic touch.

The Alexander Technique provides a means for changing habitual movement and tension patterns which may cause pain and discomfort or interfere with the development of certain skills. A brief history and description of the Alexander Technique will be presented.

Therapeutic touch is a safe and gentle way to promote relaxation, reduce pain, and accelerate healing. Developed by Dora Kunz and Dolores Krieger, RN, PhD, professor of nursing at New York University, the technique has been taught to nurses and other health professionals since 1972. An overview of theory, research, and practice will be presented. The role of therapeutic touch as a holistic treatment that patterns a person's energy field to promote self-healing will be presented from the dual viewpoint of practitioner and polio survivor.

## **Session E (Salon G)**

### **Other Therapies for Post-Polio**

F. T. H'DOUBLER, JR., MD; ED SNAPP, PT

A special article in *The New England Journal of Medicine* (Vol. 328, No. 4, January 28, 1993) reports results of a telephone survey regarding the use of unconventional therapies. Unconventional therapies were defined as medical interventions not taught widely at U.S. medical schools or generally available at U.S. hospitals. The survey concluded that roughly one in four Americans who see their medical doctors for a serious health problem may be using unconventional therapy in addition to conventional medicine, and seven of 10 such encounters take place without patients telling their medical doctor. Other therapies are generally used as an adjunct rather than as a replacement for conventional medical treatment. Polio survivors are no exception. G.I.N.I. continually receives calls and letters from survivors reporting help from other therapies.

A general invitation was issued to the providers of these other therapies to participate in this conference. Karen E. Pape, MD, FRCPC, Magee Clinic, 5160 Yonge St., Suite 505, North York, Ontario M2N 6L9, was unable to attend due to a prior commitment. Dr. Pape has treated over 200 polio survivors using Therapeutic Electrical Stimulation. The effects of hyperbaric oxygen on post-polio syndrome has been investigated by William P. Fife, PhD, Texas A&M, University Health Science Center, Texas A&M University, College Station, Texas 77843. Our meeting conflicted with the International Undersea and Hyperbaric Medical Society meeting.

F. T. H'Doubler, Jr., MD, will present information regarding his treatment of post-polio syndrome with electrostimulation of auricular (ear) acupuncture. A clinical report was recently published in the *American Journal of Acupuncture* (Vol. 22, No. 1, 1994).

Ed Snapp will present an overview of the concept, theory, and result of his special intensive treatment format for central nervous system injury, post-polio, and cerebral palsy, among others.

## **Session F (Pavilion Suite III) Post-Polio Clinics: Goals and Approaches**

RUBIN FELDMAN, MD

This presentation will describe the clinic at MacKenzie Health Sciences Center, Edmonton, Alberta. It will include admission and discharge criteria, follow up, results, and evaluation of the cost.

MARY ANN KEENAN, MD

The goal of the Albert Einstein Medical Center's post-polio management program is collaboration between the patient and health care team. Members of the team carry expertise in polio and post polio syndrome, orthopaedic, physical medicine and rehabilitation, nursing, physical therapy, and nutrition. The patient's care is managed in a holistic fashion, including the mind, body, and spirit. We begin our treatment with a personal phone call from a volunteer explaining the clinic process the day before the visit, and end in the realistic treatment plan that is both healthful and acceptable to the patient. The patient chooses what is appropriate for him/her.

## **Session G (Ft. San Carlos I) Dealing With Incontinence**

VICKI JOHNSON, RN, MSN

There are several causes of incontinence and many have the false belief that urinary incontinence is a normal part of aging. This session will focus on treatment/management of incontinence.

## **Session H (Salon E) Polio History: Our Stories Must Be Told**

KAREN HIRSCH, PhD

Personal stories have been important throughout the history of polio. These stories have changed over time. During the polio epidemics, daily stories were published under headlines like "Polio Strikes Again" and "Iron Lung Mother." During the early stages of the disability rights movement, personal life experience stories were used to help people understand how to implement Section 504 regulations, and "discrimination diaries" were used to help organize the grassroots responses to mobilize support for the Americans with Disabilities Act. There are many stories in polio history, however, that have reached only a limited audience or that have not yet been told. Oral history interviews could help us understand both the experiences of polio survivors and their culture.

## **Session I (Consul Room) The Ventilator: Technical and Trach Talk**

JERRY P. DANIEL

Some technical aspects you might want to know about the volume ventilator if part of your life, and the difference between volume ventilation and CPAP is clarified. Positive pressure ventilation via a trach can be comfortable and conducive to an active lifestyle as evidenced by alumni of the polio respiratory wards.

## **Session J (Ft. San Carlos II)**

### **Understanding EMGs**

MARTIN B. WICE, MD

Electrodiagnostic testing of the peripheral nervous system is an adjunct to the history, physical examination, other laboratory studies, and the overall evaluation of neuromuscular diseases. When used appropriately, it can result in markedly improved diagnostic accuracy. It can produce quantitative or semi-quantitative data on the severity or prognosis of the peripheral disease process. It is a relatively objective measure of peripheral neurological function. This session will explain the use of electrodiagnostic testing in the setting of the post-polio syndrome.

## **Session K (Pavilion Suite II)**

### **Resource Exchange: Disability Community Meets Aging Network**

MARGARET L. CAMPBELL, PHD

This session is dedicated to "gerontologizing polio survivors"; that is, to acquainting polio survivors with some of the normative or typically physical and psycho-social changes associated with the aging process and what resources/organizations exist to help them meet these challenges more creatively.

**Saturday Afternoon ■ June 18, 1994**

**1:30 — 3:10 pm ■ Pavilion Ballroom Salon C-D**

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

ROBERTA SIMON, RN, MODERATOR; NEIL R. CASHMAN, MD; CARL A. COELHO, PHD;  
STEVEN P. DINSMORE, DO; LAURO S. HALSTEAD, MD; VICKI JOHNSON, RN, MSN; BURK JUBELT, MD;  
THOMAS LEHMANN, MD; FREDERICK M. MAYNARD, MD; ALEXANDER SHAPIRA, MD;  
JOHAN STANGHELLE, MD, PHD; MARY T. WESTBROOK, PHD

Post-polio research is of interest to individuals experiencing new problems as well as those who are not. Researchers with a wide variety of interests will discuss their findings. Brief summaries of the conclusions from the recent New York Academy of Sciences meeting — "The Post-Polio Syndrome: Advances in the Pathogenesis and Treatment" — will be presented.

**3:30 — 5:00 ■ Pavilion Ballroom Salon C-D**

#### ***Health Care Reform: Its Impact on People with Disabilities and Caveats from International Participants***

MARTIN B. WICE, MD, MODERATOR; PAT HARVEY; JUDITH E. HEUMANN; PATRICK LEGER, MD;  
EDWARD A. OPPENHEIMER, MD; MARY T. WESTBROOK, PHD; STANLEY K. YARNELL, MD

Everyone's life has been directly or indirectly affected by our health care system. While some of the experiences have been positive, many have not. The Clinton administration has brought the need for reform to the nation's attention. What is the status of health care reform today? What issues are vital to people with disabilities? What reforms need to take place to meet those needs? How can we assure people with disabilities' needs are met? What can we learn from other countries?

**Saturday Evening ■ June 18, 1994**

**A Celebration With Friends  
(Pavilion Ballroom Salon C-D)**

Our special guest will be **Judith E. Heumann**, Assistant Secretary for Special Education and Rehabilitative Services, United States Department of Education.

**6:00 — 7:00 pm    Cash Bar**

**7:00 — 8:30 pm    Dinner and Speaker**

**8:30 — 11:30 pm    Music**

**Sunday Morning ■ June 19, 1994**

**9:30 am ■ BRUNCH**

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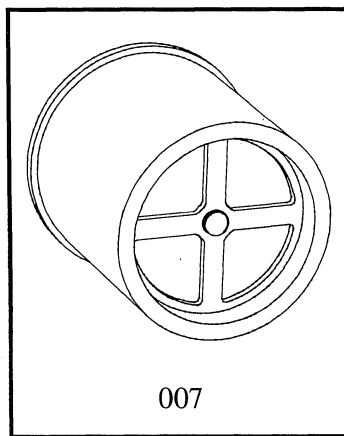
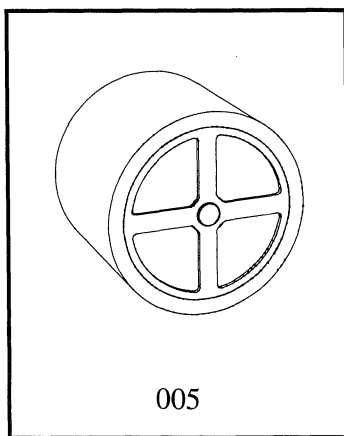
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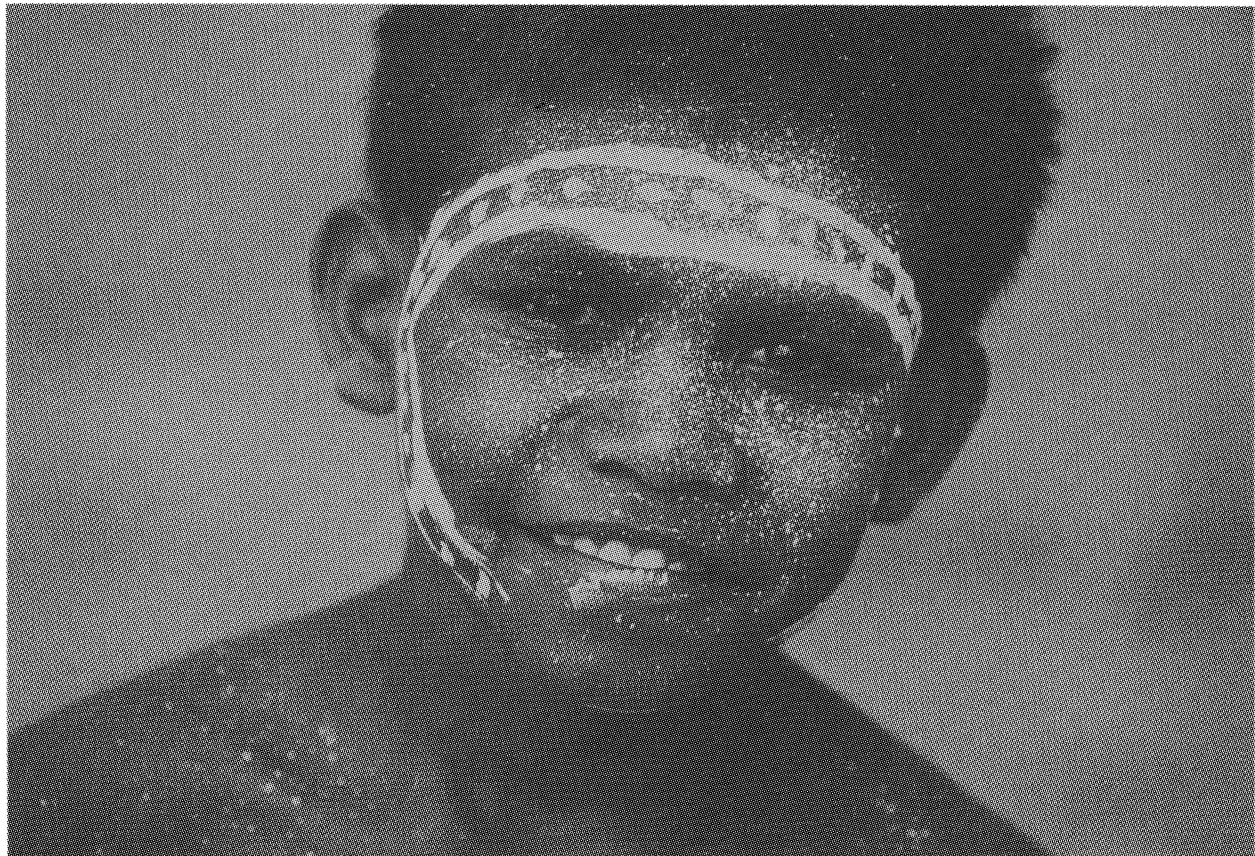
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## STATEMENT OF PURPOSE

**G**azette International Networking Institute (G.I.N.I.) is a not-for-profit 501(c)(3) 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 (IPN). 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 disability-related issues.

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